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TITLE: Primary Care and Regular Breast Cancer Screening Among
Under-Served Minority Women

PRINCIPAL INVESTIGATOR: Ann S. O'Malley, M.D.

CONTRACTING ORGANIZATION: Georgetown University
Washington, DC 20057

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Ann S. O'Malley, M.D.

7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) Georgetown University Washington, DC 20057 E-Mail: omalleya@georgetown.edu	8. PERFORMING ORGANIZATION REPORT NUMBER

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13. ABSTRACT (Maximum 200 Words) Purpose: To describe the components of primary care associated with adherence to regular breast cancer screening among low-income minority women. **Scope:** This study included secondary analyses of an existing dataset, conduction of focus groups, and development and conduction of a bilingual population-based telephone survey of lower income women over age 40 in Washington, D.C. to assess their experiences with breast cancer screening and its use in their primary care settings. Final analyses were completed during year four and are included in the appendix. Papers summarizing the final results are under review in various peer-reviewed journals. As described in the 2nd annual report, the PI obtained RO3 funding from NCI to expand the originally proposed survey from a clinic-based convenience sample to a population-based sample from throughout Washington, D.C and to include cervical and colorectal cancer screening in addition to the main focus of breast cancer screening. **Major Findings & Results:** The response rate was 85%. Overall, 66% of respondents were adherent to regular clinical breast exams and 65% to mammography. Continuity with a single primary care practitioner, comprehensive service delivery, and higher patient satisfaction with the relationships with primary care practitioners were associated with higher adherence for both tests. Compared with counterparts in non-HMO plans, women enrolled in health maintenance organizations were also more likely to be adherent to regular screening. **Significance:** Attainment of "optimal" primary care is strongly associated with adherence to breast, cervical and colorectal cancer screening for urban low income women of color. Findings guided the design of a randomized controlled trial to NCI.

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FINAL REPORT

1.0 INTRODUCTION

The overall goal of this study was to describe the components of primary care associated with adherence to regular breast cancer screening among low-income minority women. The proposed study pursued this goal by investigating features of the structure and process of primary care structure which were associated with breast cancer screening for minority women via: 1) analysis of an existing data-set of 2,600 multi-ethnic minority persons in New York City (NYC). Building on this, 2.) additional features of primary care delivery systems which promote regular breast cancer screening for under-served minority women were examined in four Washington D.C. primary care clinics. This Washington D.C. based phase includes a.) a qualitative component (focus groups) and b.) a quantitative component (survey). Finally, in conjunction with patient and provider representatives from local primary care clinics, an intervention was be developed to increase regular screening that will be implemented in the future under separate funding.

2.0 BODY:
The following is an account of the progress made in all four years toward meeting the objectives specified for the study "Primary Care and Regular Breast Cancer Screening for Under-Served Minority Women," funded by the Department of the Army as a Career Development Award.

The Specific Aims of the study were as follows:
1. To investigate features of the primary care system which are associated with higher rates of breast cancer screening for minority women, using an existing data-set of 2,600 Caribbean-, Haitian- and U.S.-born blacks, and Puerto Rican, Dominican, Colombian, and Ecuadorian Hispanics living in NYC.
2. To conduct additional examinations of the features of primary care delivery systems which promote regular breast cancer screening for under-served minority women in four Washington D.C. primary care clinics.

a. To conduct a focus group of the D.C. clinic patients and providers about perceived barriers to getting regular screening within their primary care systems.

b. Using focus group input and preliminary analyses from Aim 1, we will develop a survey focused on features of primary care systems and regular screening.

c. To administer the survey to 516 women in four primary care clinics to probe their perceived barriers to regular screening and their breast cancer screening practices.

d. To provide feedback on the survey results to the primary care clinic advisory board representatives.

3. To develop, in conjunction with the patient and provider representatives from the four primary care clinics, a primary care intervention to increase regular screening which could be implemented in the future under separate funding. (Year 4)

2.1 Revision of protocol since original application:

2.1.1 Change from a clinic-based survey to a population-based telephone survey:
For several reasons related to the quality of data and research questions, the P.I. and her mentors felt that a population-based telephone survey of women aged over 40 in the District of Columbia's lower income areas would be a preferred approach to the use of in-clinic interviews at just four clinic sites. The reasons and limitations of the new approach were outlined in an earlier annual report and this new approach was approved at the time by the Grants Officer and by the Georgetown IRB.

2.2 How the additional research costs of the revised protocol was be funded:
In December of 1998, the P.I. submitted an RO3 application to NCI for research costs of the telephone administration phase. This application budgeted for money for contract out just the phone phase of the survey's administration. The budget did not include any request for the P.I.'s salary. There was no budgetary overlap with the Dept. of Army Career Development Award proposal.

The P.I. notified her project officer from the Dept. of Army at the time that she applied for the RO3 to be sure that there were no conflicts from the Dept. of Army's perspective. The P.I. was assured that this application to NCI to supplement the research costs of this project was acceptable, and told to simply inform D.O.A. when she hears whether it will be funded.

Thus, the P.I. notified Patricia Modrow, MD, on August 4, 1999 that the RO3 application from NCI will likely be funded. This was noted by Dr. Modrow and I was informed just to note this development in the final report.

2.3. Survey Development: Year two focused on the development of a survey to assess features of primary care which promote regular screening in Washington D.C. primary care clinics.

Based on the research questions of this project, a search for existing English questions was undertaken to benefit from previously validated and reliable survey items. If necessary, these survey items were re-worded as appropriate for our study population. Use of such prior work improved the quality of our instrument.

When items measuring topics raised in the focus groups from phase I could not be found, such as for particular priorities of low-income women for primary care, new items were developed. These items were reviewed by the P.I.'s mentors and pilot tested in English prior to translation for the Spanish version. Translation of these items into Spanish will be done by an experienced translator and community health educator from Columbia. The Spanish version of the survey will be piloted among Hispanic women and reviewed by a Hispanic senior health services researcher, Dr. Perez-Stable.

The main outcome variable of interest, utilization of breast cancer screening will be measured in several ways. The additional funding from NCI (RO3 described above) will also permit the survey to be lengthened to include cervical and colorectal cancer screening as well as the main focus of breast cancer screening. To this end, we hope to determine whether features of primary care which promote

breast cancer screening are also associated with the receipt of regular cervical and colorectal cancer screening.

Use of "ever" and "recent" breast, cervical and colorectal cancer screening will be probed via previously validated items. (NHIS, etc.) Measurement of "regular" or adherent cancer screening over time presented much more complicated issues during the pilot phase. Numerous approaches to assess screening adherence were attempted including methods used by (Philips and Kerlikowske, Mandelblatt, Burnett, Kasper, Rakowski; as well as using items which the P.I. tried to develop). Any recollection of lifetime screening, or of screenings prior to the most recent test, were poor by most of the respondents. Attempts at measuring intention to get screened for breast cancer in the next year were made during piloting, but we felt that this variable could not be easily validated and given time pressures of the survey, we chose not to use an item measuring intent because its analytical usefulness was questionable.

Ultimately, for measurement of regular breast (clinical breast exam, mammogram) cervical (pap) and colorectal (fecal occult blood) screening utilization, we opted to include one item on total lifetime number of the test, and a second item which asks the women about her second to last test. (For age appropriate respondents we ask: 1)Whether she had a CBE, and a mammogram in the 2 years prior to the most recent test; 2)Whether she had a pap in the three years prior to the most recent one, and 3)Whether she had a fecal occult blood test in the two years prior to the most recent one.) We also decided to ask women in piloting about the age they were at their first screening test, and how often they had been screened since then. While less exact than obtaining the woman's "best estimate" of total lifetime screening by expecting here to recall each screening test, this question on about how often she obtained the test seemed to be easier for the woman to recall.

For the items on cancer screening knowledge, attitudes and beliefs, items were chosen from a survey by Dr. Eliseo Perez-Stable et al, which had been previously translated into Spanish using highly refined translation techniques. In terms of beliefs for African-American women, we choose items from the recent study by Lannin et al (JAMA) after personal communication with the author and review of their instrument. In piloting, items which used terminology which was unclear to respondents were dropped in favor of items from Lannins' survey which were less confusing.

Piloting of Survey
Earlier drafts of the telephone survey were piloted by the P.I. on a convenience sample of women from Washington, D.C. fitting the inclusion criteria of the study. The majority of these women were from the community health clinic, Zacchaeus Free Clinic in Washington, D.C. Piloting was done both in-person and by phone. The version of the survey included in this annual report is the one which results from revisions made during the piloting phase. A report summarizing the findings from the pilot phase is included in the appendix.

Telephone administration: Fielding of survey
In late fall/early winter of year three (Nov 1999-Jan 2000) the telephone survey will be fielded.

Setting and Population : Inclusion criteria for the survey are: being female, age over 40 years (will stratify sample to assure adequate numbers of women over age 50: Age 40-49, 50-64, 65 and over),

speaking English or Spanish, having no history of breast cancer, residing in wards 1,2,5,6,7 or 8 of the District (based on per capita incomes and poverty statistics), and living at 200% of poverty level or less.

It is estimated that there are 90,636 black women and 4,607 Hispanic women over age 40 living in the District of Columbia. (1990 U.S. Census for the District of Columbia, Summary Tape File 1). With regard to telephones: 95.8% (239,105) of all households in the District of Columbia have telephones; 93% of Hispanic households have telephones; and, 94% of black households have telephones. (1990 Census of Population and Housing, Census Bureau, Pub. No. CPH-3-331).

3.0. Data Collection: Based on the findings of the focus groups and on previously validated instruments, a telephone survey will be developed to collect more specific data on the features of primary care which promote regular breast, cervical, and colorectal cancer screening among low-income minority women in the District of Columbia. The proposed survey will collect data on the structure and process of primary care, including validated measures assessing it's the key components.

3.1 Recruitment of Sample: A list of randomly generated telephone numbers for selection of the sample, will be provided by Genesys Sampling Systems Corp. By merging phone listings from the residential white pages, and demographic information on gender, age and income from marketing data, the corporation can generate a reasonably efficient list of women aged over 40 living in the targeted wards of the District. Women over age 50 will be over-sampled to assure adequate numbers. A random-digit dial sample based on phone exchanges, targeted to the telephone exchanges of persons with the demographic characteristics and residence in the wards of interest, will supplement this list. The P.I. will work closely with Genesys Corp. in the development of this list of age and income eligible women to assure that it respects the inclusion criteria for survey participation. Distribution of the sample from each of the wards will reflect 1998 population statistics. Given the difficulty often experienced in recruiting members of high-risk populations a total of 600 telephone interviews will be completed.

A list containing 10,000 phone numbers will be generated under the assumption, based on prior work in this population,[89] that 10 phone numbers will need to be called to obtain each eligible respondent. The response rate is conservatively estimated at 60% (for this hard-to-reach group), and this would provide us with 600 completed interviews.

Completion of the 600 telephone surveys requires trained bilingual (Spanish-English) interviewers, Computer Assisted Telephone Bank (CATI), and several phones to complete the required interviews, as well as office space for the interviewers. For this reason the telephone phase of the survey will be contracted out. The survey will be completely designed by the P.I. and will be piloted initially by the P.I., on a SES-matched convenience sample of 20 women, to refine certain items and assess flow of the items. The P.I. will then give the survey and the list of phone numbers from Genesys Corp. to the telephone survey- corporation which will carry out administration of the telephone survey in the field. The contracting corporation (lowest cost estimate from Opinion Research Corporation) will re-pilot the survey in English and in Spanish. The P.I. will oversee the survey corp. in its conduction of the telephone phase. As stated in the original proposal, the P.I. will perform data quality assessment, all of the analyses on the data in SAS, including clean-up of the data, variable definition (formatting) and all exploratory and statistical analyses; she will write manuscripts on findings and disseminate results. The P.I. has experience in SAS programming and survey data analysis and will work under the guidance of

an experienced cancer prevention researcher, social scientist-cancer prevention researcher, and biostatistician.

3.2. Analysis : The original analysis plan and power calculations presented in the original proposal still apply. The only difference is the administration of the survey via telephone to a population based sample, rather than to a convenience sample from four clinics.

3.2.1 Power: Of the four screening tests which will be considered in this proposal, mammography has a low projected rate of regular use over time. For this reason, sample size calculations were conservatively based on projected "regular" mammography screening rates. Given the difficulty often experienced in recruiting members of high-risk populations a total of 600 telephone interviews will be completed. For analyses in which a dichotomous outcome variable is used (regular versus non-regular screening) this sample size will provide power of 80% at the .05 (one-sided test) significance level to detect differences of 10% or greater between screening groups (e.g., regularly and non-regularly screened women) assuming a baseline of 25% regularly screened for the most conservative screening rates.[27-28] For analyses using a continuously scaled regular screening outcome variable, this sample of 600 women will provide more than adequate power.

4.0 Strengths and Limitations: Limitations of the project include the generalizability to persons without telephones and the lack of validation of self-report data. With regard to use of the telephone, it is estimated that 94% of African-American households and 93% of Hispanic households in the District of Columbia have phones. (1990 U.S. Census for D.C., STF1) Use of population-based personal interviews would not be feasible given the resources available for the project. It is possible that those least likely to have access to primary care and to cancer screening will also be those persons without telephones, thus barriers perceived by this particular subgroup may be understated. With regard to validation of reports on screening, self-report generally overestimates the prevalence of screening. Since this study involves a population-based sample, women will likely receive care from a variety of settings in Washington, D.C. Thus, validation of self-reports through medical record review will not be practical. Characteristics which might influence the validity of self-reports, such as education, socioeconomic status and acculturation will be controlled for in analyses.

Strengths include: 1) the population-based sampling which will provide information from those with little or no access to primary care, 2) the focus on an understudied group i.e. low-income minority women, 3) a sampling plan which reflects the demographic distribution of lower income women from throughout the District of Columbia, 4) prior work with focus groups to inform the development of the survey, 5) use of trained bilingual interviewers with CATI capability, 6) unique focus on the nature of features of primary care important to regular cancer screening from the perspective of women served, and 7) the mentoring and collaboration of experienced cancer control, primary care and behavioral researchers.

5.0. Dissemination and Future Research: Findings from this project were presented at numerous national scientific meetings including: the annual Department of Army Breast Cancer meeting in Atlanta in June, 2000; the Society of General Internal Medicine Meeting in 2001, and the Association of Health Services Research Meeting in June 2001. In addition, findings were also presented to the community clinic directors in written and oral form, whose clinics allowed the P.I. to advertise for volunteers for the focus groups conducted in 1998. The project also continues to be presented in its

various stages at Georgetown University Medical Center in various forums such as the Division of Cancer Control and Prevention's research seminars. Numerous papers from the project have been published in or submitted to peer-reviewed journals. All are listed in the latter section of this final report.

6.0. Implications of project for future study: Based on survey findings, a primary care intervention to address the specific mutable aspects of primary care as they relate to cancer screening will be developed in the future. (This will be the subject of a future proposal) Together, such research has the potential to decrease the disproportionate cancer burden experienced by lower-income Black and Hispanic women.

7.0. Confidentiality and Security : All data were stripped of personal identifiers in the database and assigned a respondent I.D. number. Data were maintained electronically via entry from a CATI system and this data will be kept secure by the P.I. and by the contracting telephone survey corporation. All information provided by respondents will be confidential, no attempts will be made to link respondents to any other databases. Permission to move from a written to verbal consent has already been obtained by the Dept of Army and by the Georgetown University IRB. The survey has also been approved by the IRB.

8.0 Coursework
In year one, the PI completed a course on survey research taught by professors from the Dept. of Demography at Georgetown University's Graduate School. The P.I. pursued a self-guided study of research design under the guidance of her mentors. This included reading the texts: Designing and Conducting Health Surveys by Lu Ann Aday, and Primary Care, 2nd ed, by Barbara Starfield. The first text reviewed the planning, development and analysis of survey instruments and their data. The text on Primary Care, focused on the conceptual framework of primary care and the measurement of its attributes. Dr. Starfield's Primary Care Assessment Tool described in this text is one of the measures which will be used in this telephone survey to assess attainment of attributes of primary care and whether such attainment is associated with regular breast cancer screening. The P.I. audited a course on the design and conduct of clinical trials will be taught at Johns Hopkins School of Public Health. She also completed a course on program evaluation and health services research at Johns Hopkins. Throughout the four years, the PI participated in didactic sessions with her mentors, Jeanne Mandelblatt MD, MPH and Jon Kerner PhD, on the cultural aspects of cancer prevention and control in under-served populations and on the epidemiology of cancer in underserved populations. She also attended monthly cancer prevention and control journal clubs, health policy seminars, and cancer control program meetings.

9.0. Meetings attended

Society of General Internal Medicine, Sand Diego California, May 2001. PI presented gave an oral presentation on the main findings from the telephone survey funded under this award.

Association of Health Services Research Academy Meeting, Atlanta, Georgia. PI Presented two posters at this meeting, June, 2001.

Prevention99: American College of Preventive Medicine's annual national meeting. Presented poster on Health Information Sources Used by a Multi-ethnic community. This project was a secondary data analysis of the NYC multiethnic dataset which the P.I. analyzed in years 1 and 2 of this DOA award. The poster won the prize for the best poster. (See appendix for documentation)

In addition, the P.I. met on a tri-weekly basis with her primary mentor, Dr. Jeanne Mandelblatt to discuss all phases of the project and its development.

The P.I. attended journal club in the Division of Cancer Prevention and Control, Lombardi Cancer Center, Georgetown University. She prepared a presentation for one of the sessions as well on an article on cancer screening.

KEY RESEARCH ACCOMPLISHMENTS

Year One

- Completed Several analyses of the New York City Multiethnic Data set on Cancer Screening

- Published Paper in the American Journal of Public Health on Acculturation and Breast Cancer Screening in Hispanic Women as a result of one of these analyses of NYC data

- Developed models that to assess features of primary care that were associated with use of CBE and mammography as reported in the first annual report and in the above publication in American Journal of Public Health (submitted in year one annual report)

- Contacted directors of community clinics in Washington D.C. and conducted in-depth interviews of directors as well as visited their clinics

- Conducted four focus groups of Hispanic and African-American Women from four community health clinics in Washington D.C. to probe their experiences with cancer screening and with primary care

- Wrote report summarizing focus group findings (submitted in year one annual report)

- Abstract submitted to the Society of General Internal Medicine's Annual Meeting

Year Two

- Developed survey to collect data from women in Washington, D.C. to obtain their experiences with breast cancer screening, as well as cervical and colorectal cancer screening, in their primary care settings

- Obtained additional funding from NCI in the form of a small research grant (RO3) which will help to pay for the telephone administration of the survey and allow expansion of the survey to include cervical and colorectal cancer in addition to the focus of breast cancer

- Piloted the survey among women meeting inclusion criteria from a community clinic in Washington, D.C.

- Wrote summary report of survey pilot findings (in appendix)

- Began sample identification with the corporation which will generate the phone list of targeted random-digit-dial numbers

- Presented research study on health and cancer information sources used by a multiethnic community in NYC as a result of further analyses of multiethnic data from phase one

- Submitted and had accepted a manuscript resulting from analysis of the NYC multiethnic data on "Health and cancer information sources used in a multiethnic population," American Journal of Preventive Medicine (in appendix)

- Submitted a manuscript of focus group findings (from year one) to the Journal of Family Practice, which is under review. (in appendix)

Year Three

- Focus group manuscript published. (in appendix)

- Findings from all four focus groups were reported on a one-on-one basis to the clinic directors

- Telephone survey was administered, data collected and initial analyses conducted

- Draft of manuscript summarizing the findings from the survey (1st inclusion in appendix)

- P.I. has begun to work on an intervention design for the year four proposal with one of the primary care clinic directors

Year Four

- Continued Analyses of the Survey Data for the 1205 women.

- Reported findings from earlier focus groups to a community advisory board which included patient representatives from five different primary care clinics serving the uninsured in the Washington Metro Area

- Shared survey findings with Barbara Baldwin, the former director of Project Wish, the CDC NBCCEDP, in Washington D.C.

- Wrote a grant proposal for a randomized controlled trial of a screening intervention in lower income African Americans, and submitted this RCT as part of a KO7 application to the National

Cancer Institute. This application received a priority score of 151 and was funded on the first cycle. It begins in September of 2001.

- Wrote and submitted manuscripts to peer-reviewed journals, summarizing the telephone survey findings for the 1205 lower income women sampled in Washington D.C. about their use of breast cancer screening in primary care. The manuscripts are under review and are included in the appendix.

REPORTABLE OUTCOMES

1. Manuscripts

O'Malley AS, Forrest CB, Mandelblatt J. Adherence of Low-Income Women to Cancer Screening Recommendations: The Roles of Primary Care, Insurance and HMOs. Under review, *J Gen Int Med,* 2001.

O'Malley AS, Mandelblatt J, Lawrence W, Liang W, Yabroff R, Lynne J, Kerner J. Feasibility, Acceptability and Costs of Mobile Multiphasic Cancer Screening, *J Health Care Poor and Underserved* in press vol 13, 2001.

O'Malley AS, Forrest CB. Primary Care Performance and the Physician-Patient Relationship for Low-Income Women. Submitted to *J Gen Int Med*, Mar 2001.

Yabroff KR, **O'Malley AS**, Mangan P, Mandelblatt J. Inreach and Outreach Interventions to Improve Mammography. In press, *JAMWA*, Mar 2001.

O'Malley AS, Mandelblatt J, Johnson A, Kerner J. "Acculturation and Use of Breast Cancer Screening in Urban Hispanic Women." *American Journal of Public Health*. 1999;89:219-227.

O'Malley AS, Kerner J, Johnson L. Are We Getting the Message Out to All? Health Information Sources and Ethnicity. *American Journal of Preventive Medicine.* 1999;17 (3) In press.

O'Malley AS, Forrest CB, O'Malley PG. Low Income Women's Priorities for Primary Care. *Journal of Family Practice*. 2000;49:141-146..

Mandelblatt J, Gold K, **O'Malley AS**, Taylor K, Cagney K, Hopkins JS, Kerner J. "Use of Breast and Cervix Cancer Screening by Multi-Ethnic Elderly Women." *Preventive Medicine.*1999; April 28 (4):418-425.

Meeting Presentations:

O'Malley AS, Forrest CB, Mandelblatt J. Adherence of Low-Income Women to Cancer Screening Recommendations: The Roles of Primary Care, Insurance and HMOs. Oral presentation at the **Society of General Internal Medicine's National Meeting,** May 2001, San Diego

O'Malley AS, Forrest CB, Mandelblatt J. Adherence of Low-Income Women to Cancer Screening Recommendations: The Roles of Primary Care, Insurance and HMOs. Poster presentation, Sunday June 10, 2001. Poster. **Academy for Health Services Research and Health Policy**. Annual Meeting, Atlanta.

O'Malley AS, Forrest CB. Primary Care Performance and Lo-Income Women's Patient-Physician Relationships, Sunday June 10, 2001. Poster. **Academy for Health Services Research and Health Policy**. Annual Meeting, Atlanta.

O'Malley AS, Forrest CB, Mandelblatt J. Primary Care and Regular Breast Cancer Screening. Era of Hope 2nd annual meeting, Atlanta Georgia, June 8-12, 2000.

O'Malley AS, Kerner J, Johnson L. Are We Getting the Message Out to All? Health Information Sources and Ethnicity. Presented at the 16th Annual National Preventive Medicine Meeting, Prevention99. Arlington VA, March 18-21, 1999.

4. Awards

Best Faculty Poster Award at the American College of Preventive Medicine's and American Teacher's of Preventive Medicine's annual meeting, *PREVENTION 99*
For: **O'Malley AS**, Kerner J, Johnson L. Are We Getting the Message Out to All? Health Information Sources and Ethnicity. Prevention99: American College of Physician's Annual Meeting.

5. Funding Obtained based on Work Supported by this Award

NCI-RO3. August 1999-December 2001. (Principal Investigator) Community-Based Primary Care and Regular Cervical, Colorectal and Breast Cancer Screening in Low-Income Women. (Explained in detail in the above annual report.)

NCI-KO7 Starts August 2001. (Principal Investigator) Decreasing Disparities in Cancer Screening Among Uninsured African-Americans.

CONCLUSIONS:

Attainment of "optimal" primary care is strongly associated with adherence to breast, cervical and colorectal cancer screening for low income and minority women. The specific features of primary care most strongly associated with adherence to all types of recommended cancer screening for these women were: 1) Continuity with a usual source of care and with a specific clinician at that site which one sees for more (rather than fewer) of her visits, 2) Comprehensiveness of non-cancer screening services: e.g. practices which emphasized the comprehensive aspect of primary care with respect to counseling patients around health behaviors (non-cancer behaviors were measured). For mammogram and fecal occult blood testing, an additional feature of primary care which was associated with screening adherence was the coordination of care.

Women whose ambulatory systems reflected features of "optimal" primary care were more likely to receive all types of cancer screening and to be adherent to screening over time, regardless of their insurance status or socioeconomic status. While insurance status alone is a very important predictor of receipt of screening when assessed in models that do not fully account for the various components

of primary care, it no longer predicts receipt of screening when one includes in the models the specific features of primary care. These findings argue that it is not insurance or financial access alone that facilitate screening utilization; but that when insurance facilitates entry into more "optimal" primary care systems women are more likely to adhere to screening recommendations. These findings carry special importance for policy implications for efforts to increase higher risk minority women's use of needed health care services. Providing women with insurance alone, while an important first step, will not guarantee use of recommended services unless it also facilitates their entry into ambulatory systems that provide optimal primary care.

Strengths and Limitations: Limitations of the project included the generalizability to persons without telephones and the lack of validation of self-report data. With regard to use of the telephone, it is estimated that 94% of African-American households and 93% of Hispanic households in the District of Columbia have phones. (1990 U.S. Census for D.C., STF1) Use of population-based personal interviews would not be feasible given the resources available for the project. It is possible that those least likely to have access to primary care and to cancer screening will also be those persons without telephones, thus barriers perceived by this particular subgroup may be understated. With regard to validation of reports on screening, self-report generally overestimates the prevalence of screening. Since this study involved a population-based sample, women will likely receive care from a variety of settings in Washington, D.C. Thus, validation of self-reports through medical record review was not be practical. Characteristics which might influence the validity of self-reports, such as education, socioeconomic status and acculturation will be controlled for in analyses.

Strengths include: 1) the population-based sampling which will provide information from those with little or no access to primary care, 2) the focus on an understudied group i.e. low-income minority women, 3) a sampling plan which reflects the demographic distribution of lower income women from throughout the District of Columbia, 4) prior work with focus groups to inform the development of the survey, 5) use of trained bilingual interviewers with CATI capability, 6) unique focus on the nature of features of primary care important to regular cancer screening from the perspective of women served, and 7) the mentoring and collaboration of experienced cancer control, primary care and behavioral researchers.

Implications: Assessment of the relationship between mutable features of primary care which promote early and ongoing use of recommended cancer screening in low-income women of color will help to target early cancer intervention efforts toward this traditionally under-served population. These findings are helping to develop a better understanding of the aspects of primary care which are most important to low-income women, and the role which attainment of those particular features plays in obtaining regular cancer screening. Findings from this DOA-CDA guided the design of a future RCT intervention that emphasizes important features of primary care in order to increase adherence to screening. This RCT was part of a KO7 application submitted to NCI by the PI and will be funded starting in the fall of 2001. The KO7 extends the lessons learned from this DOA award to the screening area of colorectal screening as well as to breast and cervical cancer screening for lower income and uninsured African-Americans. This KO7 includes colorectal cancer screening in the RCT rather than breast cancer screening because the survey findings from this CDA, as well as data from Washington DC and from the clinic directors serving the population of interest, indicate that breast cancer screening rates for lower income Blacks and Hispanics are at rates now comparable to those of the non-Black, non-Hispanic population. Interviews with all of the clinic directors indicated, like

national data, that colorectal cancer screening rates are low among the lower income population, especially among African-Americans who suffer disproportionate morbidity and mortality from colorectal cancer. Lessons learned from this DOA-CDA breast cancer screening project will inform the colorectal cancer screening RCT. The KO7 will also assess breast cancer screening among the female participants. In addition the KO7 funds the PI to do analyses of the Medical Expenditure Panel Survey linked with the National Health Interview Survey to analyzed cancer screening behaviors (breast, cervical and colorectal) for lower vs. higher income persons nationwide.

Personnel receiving pay from this grant were:

1. Ann S. O'Malley MD, MPH (P.I.)

2. Consultants who moderated the focus groups:
   Nhora Berrara Murphy
   LaVeda Evelyn DeVone

3. Professional Translators/Interviewers:
   Nhora Berrara Murphy of Media Network

APPENDICES

Please Note: The 1st attached document: "Adherence of Low-Income Women to Cancer Screening Recommendations: The Roles of Primary Care, Insurance and HMOs." (O'Malley et al.) summarizes the major findings from the population-based telephone survey referred to in the body of this final report.

Adherence of Low-Income Women to Cancer Screening Recommendations: The Roles of Primary Care, Health Insurance, and HMOs

Ann S. O'Malley[1] MD, MPH
Christopher B. Forrest[2], MD, PhD
Jeanne Mandelblatt[1], MD, MPH

1. Departments of Oncology and Internal Medicine, Georgetown University Medical Center, Washington, D.C.

2. Department of Health Policy and Management, Johns Hopkins School of Hygiene and Public Health, Baltimore, MD.

Corresponding Author:

Ann S. O'Malley, MD, MPH
2233 Wisconsin Ave., NW
Suite 440
Washington, DC 20007

email: omalleya@ georgetown.edu
phone (202) 687-0862   fax (202) 687-0305

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ABSTRACT

Background: African-American and low-income women have lower rates of cancer screening and higher rates of late-stage disease than counterparts.

Objective: To examine the effects of primary care, health insurance and HMO participation on adherence to regular breast, cervical and colorectal cancer screening.

Design: Random-digit-dial and targeted household telephone survey of a population-based sample.

Setting: Washington, D.C. census tracts with $\geq$ 30% of households below 200% of federal poverty threshold.

Participants: 1205 women over age 40, 82% of whom were African-American.

Main Outcome Measures: Adherence was defined as receipt of the last two screening tests within recommended intervals for age.

Results: The survey completion rate was 85%. Overall, 75% of respondents were adherent to regular Pap smears, 66% to clinical breast exams, 65% to mammography, and 29% to fecal occult blood test recommendations. Continuity with a single primary care practitioner, comprehensive service delivery, and higher patient satisfaction with the relationships with primary care practitioners were associated with higher adherence across the four screening tests, after considering other factors. Coordination of care also was associated with screening adherence for women age 65 and over, but not for the younger women. Compared with counterparts in non-HMO plans, women enrolled in health maintenance organizations were also more likely to be adherent to regular screening (e.g. OR Pap 1.89, 95%CI 1.11-3.17; OR Clinical breast exam 2.04, 95%CI 1.21-3.44; OR Mammogram 1.95, 95%CI 1.15-3.31; OR fecal occult blood test 1.70, 95%CI 1.01-2.83.)

Conclusions: Organizing healthcare services to promote continuity with a specific primary care clinician, a comprehensive array of services available at the primary care delivery site, coordination among providers, and better patient-practitioner relationships are likely to improve inner-city, low-income women's adherence to cancer screening recommendations. Primary care performance is an important determinant of adherence to regular cancer screening for low-income women.

Key words: breast- cervical- and colorectal neoplasm/ prevention and control*, primary health care, poverty, insurance, women, ethnicity/black/ African-American.

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INTRODUCTION

Low-income women have disproportionate breast, cervical and colorectal cancer morbidity and mortality.[1-7] African-Americans are disproportionately represented among women with low incomes. A large portion of the income and race-associated cancer morbidity and mortality is related to lower use of regular cancer screening.[6-11] This differential in screening adherence persists despite evidence that regular screening reduces mortality from 30-70%.[12-19] While "ever" and "recent" screening rates are increasing for all groups,[20-22] fewer data are available on factors associated with adherence to recommended [18] use of regular screening, especially for low income and minority women.[23-32]

Having a regular source of care [24-29] or a physician recommendation for screening [30-32] are two of the most consistent predictors of cancer screening among women of all income and demographic groups. If this "usual source of care" is a primary care site, then a "recent" cancer screening test is more likely to have occurred.[28-29] However, among those studies that assessed whether the woman had "a usual source of care," most did not measure specific characteristics of primary care provider settings,[33] where screening is most often initiated. The studies that focused on the process and structure of primary care [28-29] have not concurrently measured patient attitudes and beliefs, with respect to screening utilization, and targeted lower income persons.[34-37]

We examined the effects of primary care and health insurance--including enrollment in health maintenance organizations-- on adherence to breast (clinical breast exams and Mammograms), cervical (Pap test) and colorectal (fecal occult blood test) cancer screening over time among a population-based sample of women living in low-income urban census tracts. We hypothesized that women with better primary care delivery sites-- defined as care which is continuous,

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comprehensive, accessible, coordinated, and which involved a strong patient-clinician relationship-- would have higher rates of adherence to cancer screening, even in the face of strong socioeconomic, insurance and cultural belief barriers to screening.

METHODS

Survey Design and Sampling

Sampling Strategy: Inclusion criteria were being female, age over 40 years, residing in a Washington, D.C census tract with at least 30% of households having an income < 200% of the 1999 poverty threshold for a family of four.[38] The target sample size was 1200. Our strategy balanced efficiency with a community-based sampling method. A professional sampling system (Genesys Sampling Systems) generated a list of telephone numbers to obtain a sample of 25% random-digit-dial and 75% targeted listed households. The Random Digit Dialing sample was generated from the set of all telephone exchanges that service the lower income census tracts throughout Washington, D.C. To oversample women with low incomes, the listed household sample was merged with demographic information, from census and marketing data, which targeted inclusion criteria.

While controversy exists over screening women over age 65 with pap smears and women under age 50 with mammograms, we chose to include these age groups in order to examine whether associations between primary care, insurance variables and screening were present for them as well.

Instrument Development and Data Collection: The telephone survey was developed using focus groups, prior research,[24, 39-44] and pilot testing. Trained, female bilingual (Spanish/English)

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interviewers conducted a computer-assisted (CATI) telephone survey between January-March, 2000. An original and up to five call-backs were attempted to reach each residence. Most calls were made between the hours of 3pm and 10pm on weekdays and weekends, but calls were also made outside of these hours and a toll-free number was provided. The survey took on average 25 minutes to complete. The completion rate was 85%, defined as the proportion of eligibles contacted who consented to and completed the survey.

Variables: Our dependent variables were adherence to cervical, breast and colorectal cancer screening. For each test, adherence was defined as self-reported receipt of a "recent" and routine age-appropriate screening test, plus receipt of a test just prior to that most recent test during the recommended interval.[18, 45] For Pap smears, we used receipt of a recent pap in the past 3 years, and a pap during the three years prior to the most recent. For clinical breast exam (CBE), we used a recent CBE in the past year plus a CBE during the two years prior to this most recent CBE. For Mammogram, we used a recent and routine mammogram in the past two years, plus a mammogram during the two years prior to this most recent one. For adherence to the fecal occult blood test (FOBT), we used a recent FOBT in the past year plus an FOBT during the two years prior to the most recent one, for women over age 52. Since screening rates with flexible sigmoidoscopy are so low in the population of interest, and because most ambulatory settings serving these women did not have these capabilities at the time of the study, this test was not measured.

Independent Variables were age (41-49; 50-64, ≥65 years), household income, race/ethnicity, education, work status, marital status, family size, whether one owns/rents home, health status,

cancer knowledge/attitudes and beliefs,[41-44] insurance status and plan type, features of primary care and the patient-clinician relationship.[40] The items on cancer attitudes and beliefs were those found in prior studies to be most strongly associated with late-stage diagnosis of cancer or with screening in similar populations.[42,44] (Instrument available from authors). We employed the Institute of Medicine's definition of primary care as "the provision of integrated, accessible health care services by clinicians that are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community."[46] Primary care key features measured were comprehensive service delivery, coordination, continuity with a single provider, accessibility,[42-47] and the patient-clinician relationship. We adapted the Primary Care Assessment Survey to develop the primary care variables.[40] A summary of the items measuring the primary care features is in the appendix.

The "Visit Continuity" variable was created to have four mutually exclusive categories: (1) No usual site of care, (2) Having a usual site but no regular clinician at that site (reference group), (3) Having a usual site and a regular clinician at that site which one saw for only some of her sick and well visits, (4) Having a usual site and a regular clinician which one saw for most of her sick and well visits. To create these last two categories, survey items asked: "When you go for a check-up or routine care, how often do you see your regular doctor as opposed to an assistant or partner?"; and, "When you are sick and go to the doctor, how often do you see your regular doctor as opposed to an assistant or partner?" Response options were: Always, A lot of the time, Some of the time, Almost Never, and Never. If a woman had a regular clinician at her usual site of care and if she answered "Always" to these last two questions, she was put in the group with the highest level of visit continuity.

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Data Analysis: Univariate, bivariate and stratified analyses with chi-square tests, were done prior to multivariate modeling. To analyze our measures of screening adherence, we created a dichotomous outcome variable (adherent vs. non-adherent). Extensive analyses assessed for confounding. We also assessed for interaction between insurance, income, health status, and each of the primary care variables separately with respect to receipt of each screening test.

Logistic regression models were then built. Socioeconomic, demographic and cancer attitudes and beliefs variables were added first to control for women's propensity to obtain screening services. Additional groups of variables were added in a stepwise fashion to examine their impact on adherence controlling for propensity of women to obtain screening services. Specifically, we added the primary care variables next, followed by the insurance and HMO variables. This sequence was chosen to determine if insurance and use of HMOs increased the explanatory power of the model, once primary care delivery factors were controlled. Final models were based on variables which had an association ($p \leq .20$) with screening adherence in stepwise logistic regressions, or which were consistently associated with screening in univariate analyses, or which were associated with screening in prior literature. Since comprehensiveness of non-cancer screening services was so likely to overlap conceptually with cancer screening, this construct was not included in the logistic regression models.

Since women age 65 and over are likely to have Medicare, with implications for coverage of screening and other services, all multivariate models were run both for the entire group combined, and then separately for women <65 and women ≥65. Model fits were good as assessed by the Hosmer-Lemeshow test and c statistic.[48-49] We also calculated the population

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attributable risk to assess the association between the most significant primary care variables and screening.[50-51] Prior to calculating attributable risk, we modeled the dependent variable of nonadherence in order to permit a more intuitive and meaningful interpretation of the population attributable risk estimate.

RESULTS

Table 1 describes the sample. For comparison, we used the 1999 Current Population Survey[52] (CPS) data for Washington, D.C. to describe the universe of women over age 40 living in the census tracts sampled. Compared with the CPS estimates, the study population was older, had less formal education, was poorer and more likely to be African-American. This reflects success in our targeting procedures for obtaining a large sub-group of low-income women.

Study population rates of uninsurance for women age 41-64 (13.2%) were slightly higher than national rates (7%) for the same age group.[10] Seven percent of those with a regular clinician identified an obstetrician-gynecologist as that clinician. The majority of respondents (62%) used private doctors' offices or an HMO. Twenty-seven percent attended Community Health Centers or other non-profit community health clinics.

Table 2 presents the unadjusted percentages of women adherent to screening recommendations according to respondent, primary care delivery site, and health system characteristics. For all types of insurance, women aged 65 and over were less likely to be adherent to screening than were women under age 65. The largest associations with screening adherence were found with the primary care variables. For example, continuity of care was significantly associated with adherence to all four screening tests. For each test, the largest increase in adherence was found

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for those who had a usual source of primary care compared with those without one. However, there were also substantial increases in screening adherence among those who had a specific practitioner at their primary care delivery site, compared with those without one. Likewise, longer relationships with primary care practitioners significantly increased the chances of adherence to screening recommendations. Respondents with more "comprehensive" primary care sites in terms of non-cancer counseling, screening and general health services, were more likely to be adherent to all cancer screening tests. Adherence to tests that are done on-site at the primary care clinician's office (pap and CBE) was higher among women whose levels of trust, compassion and communication with their primary care practitioner were higher.

Only one of the cancer attitude and belief items was consistently associated with adherence across all four cancer screening tests: "Going to the doctor for check-ups when well" ($p \leq .01$). None of these attitude or belief items were consistently associated with screening adherence in the logistic regression models (Tables 3-4).

Logistic Regression Analyses: Tables 3 and 4 present the adjusted odds ratios from the logistic regression models done separately for women age <65 and ≥65. For women under age 65, continuity of care (with a place and with a specific clinician) was strongly associated with screening adherence. For women ≥65, continuity of place was associated with adherence. Respondents whose primary care delivery sites were more "comprehensive" were more likely to be adherent with recommended pap tests and CBE if aged <65 years, and with all four tests if ≥ 65 years. Better coordination of specialist care outside of the office was also associated with CBE, mammograms and FOBT adherence among older women. Trust, communication and

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compassion aspects of the patient-clinician relationship were associated with adherence for pap tests and FOBT.

For women under age 65, comparing those with the highest level of continuity (Having a specific clinician which one saw for most visits) versus those with the second level of continuity (Having a usual site of care but no specific clinician at that site), the attributable risk percents were as follows: Pap nonadherence 29.7%, CBE nonadherence 14.7%, Mammogram nonadherence 12.3%.

Although having private insurance was significantly associated with adherent screening for all tests in the unadjusted analyses, once the primary care variables were entered into the models, only one of the insurance categories, i.e. private HMO, was associated with screening. Compared with the reference group, women with Medicaid and/or Original Medicare (fee-for service) only, private HMO enrollees were significantly more likely to be adherent to screening.

Since we were interested in further exploring whether the higher adherence to cancer screening among private HMO enrollees was associated with the primary care performance of those arrangements, we compared women's reports of primary care performance across insurance and plan types. Women in private HMOs (< 65 year olds) and Medicare HMOs (≥ 65 year olds) had lower ratings of their primary care characteristics, than did women in private indemnity plans. For example, 37.6% of women in HMOs rated their continuity as highest whereas 64.3% of women in private indemnity plans rated their continuity as highest (p=.001). Only 51.9% of women in HMOs rated their sites' organizational accessibility as highest, vs. 66.9% of women in private indemnity plans (p=.001). Similar differences existed for the other characteristics of

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primary care: Trust in the regular physician 60.5% HMO vs. 77.5% Private FFS, Coordination of specialty care 27.4% in HMO vs. 41.4% in Private indemnity (p=.001 for each comparison).

Finally, we re-ran the final logistic regression models to examine whether there were differences for women whose regular clinician was an ob-gyn doctor versus other types of clinicians. Having an ob-gyn as the regular clinician significantly increased the odds of adherence to mammography 2.5 times (p=.01) for women under age 65. However, having an ob-gyn, rather than another type of primary care clinician, was not significantly associated with Pap, CBE, or FOBT adherence for any of the women, and was not significantly associated with mammography for women age 65 and over. Also, inclusion of this covariate did not change the relationships between the primary care variables and screening adherence.

DISCUSSION

This study is the first to examine the role of specific characteristics of primary care delivery on adherence to cancer screening for a population-based sample of inner city, low-income women. Despite socioeconomic, belief, and insurance barriers, women with primary care delivery sites characterized by more continuity of care, comprehensive services, and coordination, were more adherent to regular cancer screening. Additionally, higher levels of patient-clinician trust, compassion and communication were associated with more adherence to cancer screening. Finally, being in a private HMO was the only insurance category significantly associated with screening adherence after controlling for the primary care characteristics of women's delivery sites.

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While having any form of private insurance was associated with screening adherence in the unadjusted analyses, after controlling for primary care characteristics, being in a private HMO was the only insurance category that remained associated with screening adherence. Other forms of insurance (public, private indemnity i.e. fee-for service and PPO) did not remain associated with screening adherence once the specific primary care variables were entered into the models. Women in private HMOs and Medicare HMOs rated those sites significantly poorer on primary care performance than did women in private indemnity plans. So, it is unlikely that the higher cancer screening rates among HMO participants were due to stronger primary care performance by those settings. One might speculate that women in HMOs were more likely to be adherent to screening than women in non-HMOs because managed care plans' participation in HEDIS[53] provides them incentives to emphasize cancer screening. This finding that HMOs perform well on the delivery of cancer screening services is supported by other studies. [54-55]

In conjunction with the major primary care findings of this study, this additional finding on insurance suggests several things about its relationship to cancer screening. Having insurance, in general, is an important facilitator of entry into healthcare. However, it seems that the characteristics--i.e. structure and process--of a woman's primary care delivery system are more important for assuring adherence to screening. Among the primary care characteristics, continuity of care appears to have the largest positive impact on cancer screening adherence. Overall, this study adds to the growing literature finding that delivery system characteristics, rather than simply the presence of insurance, are more powerfully associated with health care service use. [27, 56] In addition, our findings suggest that both the structure of a woman's primary care delivery site (e.g., continuity with a site and a specific clinician) as well as the process of

care at that site (better patient-physician communication and trust) are important mediators of cancer screening adherence.

For women over 65, we did not find that financial accessibility of primary care, measured in this study as the perception of out-of-pocket costs for physician-visits, prescriptions and prescribed treatments, influenced screening utilization. Prior research found that lower cost-sharing is associated with greater use of preventive services.[57] Women with Original Medicare must pay 20% of the cost of pelvic exams (done with pap) or physical exams (CBE).[58] However, State Medical Assistance-- via the Qualified Medicare Beneficiary (QMB) and the Specified Low Income Medicare (SLMB) Beneficiary Programs-- help low-income women with Medicare Part B premiums, deductibles and coinsurance. For women under 65, the National Breast and Cervical Cancer Early Detection Program's coverage of cervical and breast cancer screening for qualified women was likely an important contributor[59] to the absence of an association between perceived financial access and screening.

Since this study identified women randomly in the community, rather than a convenience sample of clinic attendees, it has public health policy relevance, because it focuses on all women, not just those attending medical clinics or offices. This study also has limitations: First, these data may not generalize to persons without telephones or in rural areas. It is estimated that 94% of African-American households in the District of Columbia have phones.[60] Second, the cross-sectional design limits interpretation of the directionality between independent variables and screening utilization. For example, women with a more recent CBE may be more likely to report having a more continuous relationship with a provider. However, prior work has found a

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potentially causal relationship between having a usual source of care and the receipt of screening services.[27] In addition, the exposure-response relationship between some of the primary care variables and adherence provide further support for a potentially causal association.

Self-report data generally overestimate screening rates.[61-62] Respondents received care from many different sites. Thus, validation of self-reports through medical record review was impractical. Characteristics that might influence self-report validity, such as education and socioeconomic status, were controlled for in analyses. The validity of respondents' classification of their insurance status cannot be ascertained. The percentage of our sample aged ≥ 65 with Medicare Managed Care (17.6%) was higher than among all women age ≥ 65 in Washington D.C. (10.4%).[63] This likely reflects the fact that Medicare managed care plans primarily serve urban seniors with incomes under $20,000.,[64] a group targeted by our sampling strategy.

We did not determine the proportion of our sample receiving care from both a primary care clinician and a gynecologist—the so-called 'dual PCP' arrangement. The likelihood of obtaining screening tests might increase among those with both types of clinicians, while continuity of care would decrease because of the need to see multiple providers for primary care. Nationally, about one-third of women over age 18 receive care from both a gynecologist and a primary care provider.[65] This percentage is likely to be much lower in older, lower income women in medically under-served areas.[65-66] Finally, while the sample size of this study was adequate to detect subgroup differences in receipt of pap smears, CBE and mammograms, we lacked power to fully assess all relationships between the independent variables of interest and FOBT.

Implications:

One of the most important associations in our study was between continuity with a specific primary care clinician and cancer screening adherence. We calculated attributable risks to provide measures of how screening adherence would change if non-elderly women without a specific primary care clinician were linked to a specific clinician at their primary care delivery sites. Our findings revealed that, if there were a causal association between continuity and cancer screening adherence, pap smear adherence would increase by 30%, CBE by 15% and mammography by 12% among women without a primary care clinician. These are substantial effects potentially attainable by reorganizing primary care services to promote continuity for inner-city, low-income women.

Although progress has been made in narrowing the gap in screening rates between minority and non-minority populations, barriers to screening persist even among the insured. Assessment of the relationship between mutable features of primary care which promote early and ongoing screening will help to target intervention efforts. For example, not all insured persons have their cancer screening coordinated through a primary care provider. Some obtain screening in mass screening programs, but fail to obtain coordinated follow-up and repeat screening. The relationships found in this study between continuity of care and adherence to screening over time, suggest that absence of such primary care features in screening programs may result in poorer adherence. Health care education aimed at patients should stress the importance of identifying a primary care provider and of obtaining screening through that provider.

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Another implication of our study is that efforts to eliminate the disparities in late-stage cancer among lower income and minority women might focus on developing performance assessment tools to include process indicators of the quality of primary care delivery, (e.g. continuity of care, comprehensive service delivery). Disease-specific performance measures do not create adequate incentive among health plans to deliver "optimal" primary care to their members.

Our results also suggest that efforts to decrease the disparity in potentially avoidable cancer morbidity and mortality among low-income women, should take a broad perspective of their health care systems. Cancer screening needs to be considered in the context of the totality of woman's health care needs and in the context of the practitioner with whom she has an ongoing relationship. Regardless of the barriers women face to screening, having a high quality primary care delivery site is the strongest predictor of adherence to screening for this at-risk group. Thus, providing health insurance is a necessary but not sufficient step toward improving adherence to recommended cancer screening services. Policy efforts toward increasing insurance coverage must be accompanied by incentives to increase primary care attainment among both newly and previously insured groups.

Acknowledgement:

Table 1. Characteristics of the Study Sample (N=1205) compared with women living in the same census tracts.[Ψ]

Characteristic:	Study Population (n=1205) %	Women in Same Census Tracts as the Study Population %
Age Mean (years)	64.8 yrs	59.7 yrs
Categories: 41-49 years	16.3%	25.5%
50-65	28.4	38.7
≥ 65	55.3	35.8
Education (Highest completed)		
< 12 years	26.3	21.8
HS grad/GED	33.5	27.7
≥ Some college	40.2	50.5
Income		
Don't Know/Refused (most similar to the <$10K group)	26.9	
<$10K	11.5	11.5
$10-20 K	15.9	14.4
$20-30K	15.1	17.0
$30-40 K	11.4	10.3
$>40K	19.2	46.8
Self-identified Ethnicity/Race		
Black/African-American	82.7	67.0
Caucasian	6.6	25.9
Hispanic/ Other	3.7	7.1
Refused	7.0	
Owns Home (vs. Rents)	66.2	63.5
Work Status		
Retired/Disabled	62.6	30.7
Working Full-time	24.3	41.1
Working Part-time	6.4	9.1
Unemployed/ Homemaker/ Student/Refused	7.2	19.1
Married/living as married	26.5	37.4
Family Size	2.1 (mean)	2.3 (mean)
>=4 persons/household	12.4	15.6
Health Status (self-assessed)		
Poor-Fair	26.2	
Good	36.4	Not available
Very good-Excellent	37.4	
Has a regular personal doctor/nurse	84.8	Not available
Health Insurance for Any Period During the Past 12 Months		
Public Only	22.8	
Private (may also have had Medicare/Medicaid)	67.9	
Uninsured for the <u>entire</u> past 12 months: < 65 year olds	13.2	Not available
≥ 65 years	6.3	

* D.C. Current Population Survey, 1999 for Women over age 40 in the same census tracts; Note, CPS presents rates for all ages combined (uninsured not available from CPS stratified by these age categories)

[Ψ] Census tracts where at least one-third of the population lives at or below 200% poverty threshold.

Table 2. Screening Adherence by Features of the Primary Care Delivery Site, Insurance and HMO Participation.

	No. of Women	Pap Test %	CBE %	Mammogram %	FOBT %
Features of the Primary Care Delivery Site:					
Visit Continuity—with a Primary Care Delivery Site & Clinician		**	**	**	*
No Site of Care	34	41.2	23.5	29.4	11.5
Has a Site of Care, But No Regular Clinician	149	68.5	60.4	53.0	24.3
Has Primary Care Site & Regular Clinician, But Sees for only Some Visits	391	76.9	64.7	66.5	33.3
Has Primary Care Site & Sees Same Regular Clinician For Most Visits	631	76.7	71.5	69.7	28.9
Duration of the Relationship		**	*	**	*
Has had Primary Care Delivery Site for < 6 months	71	61.9	57.7	50.7	21.0
Has had Same Primary Care Site for 6-24 months	273	73.6	64.8	63.4	26.3
Has had Same Primary Care Site for > 24 months	826	77.7	69.7	69.0	31.9
Access—Organizational		**	*		
Lower	531	71.2	63.5	64.6	29.1
Higher	674	77.6	69.0	66.2	29.6
Access-Geographic			*	**	
Lower	588	73.5	63.9	62.1	27.9
Higher	598	76.9	69.2	69.4	31.0
Access-Financial		**	*		
Lower	308	70.8	63.3	62.7	29.1
Higher	692	78.7	70.6	66.9	30.0
Don't Know/Missing	205				
Comprehensiveness—All health needs met by regular provider		*	**	*	*
Lower	591	72.6	63.6	62.6	25.9
Higher	575	78.3	71.0	69.4	32.8
Comprehensiveness—of Non-cancer Screening Tests		**	**	**	**
Lower	190	55.8	40.5	47.4	13.8
Higher	1007	78.9	72.0	69.4	32.2
Comprehensiveness—Counseling around diet, alcohol and tobacco		**	**	**	*
Lower	369	65.6	58.5	60.4	25.3
Higher	831	79.0	70.4	68.1	31.5
Patient Physician Relationship—Compassion		**	**	**	*
Lower	648	70.0	62.0	61.6	26.7
Higher	557	80.0	71.8	70.0	32.5
Patient Physician Relationship—Trust			*		
Lower	321	72.6	62.0	63.8	25.2
Higher	871	75.9	68.3	66.5	30.9
Patient Physician Relationship—Communication		**	**		
Lower	555	70.6	62.9	63.1	28.2
Higher	635	79.2	70.2	68.4	31.1
Coordination – of Specialist Care (N=748)			**		**
Low	133	75.9	63.2	63.2	20.0
Mid	354	79.7	69.2	71.7	32.7
High	267	80.9	77.9	70.4	37.4
HEALTH SYSTEM/ INSURANCE STATUS:					
< 65 years old		**	**	**	**
Uninsured	70	71.4	61.4	50.0	10.0
Public Only (Medicaid$^\Omega$ &/or Medicare only)	88	78.4	63.6	43.2	26.5
Private HMO	145	90.3	75.8	80.0	43.4
Other Private (may have public too)	229	84.7	78.6	65.9	23.6
≥ 65 years old		**	*	**	**
Uninsured	41	60.9	58.5	53.7	17.1
Original Medicare (may have Medicaid too)	210	60.0	55.2	59.0	25.7
Medicare Managed Care	117	74.3	70.9	75.2	39.3
Medicare + Private Medi-Gap	295	72.5	61.7	70.5	31.9

**=p≤.01   *p<.05   for the column group.   CBE=Clinical Breast Exam

© For FOBT n=990 since adherence to FOBT only applies to women age ≥ 52 (allows for woman ≥ 50 to have their first FOBT).

$^\Omega$ Includes Medicaid managed care enrollees.

^{f} "Other private" includes Federal Employees Health Benefits Program (FEHBP), Champus and other plans.

"Adherence" is defined for each screening test as having obtained the last two tests within age appropriate intervals based on NCI, ACS, USPS guidelines: Ex. Mammogram adherence = last mammogram was for a routine screening exam, was within the past two years, and also had a n during the immediate two years before that "recent" one.

Table 3. Factors Significantly Associated with Adherence to Cancer Screening Recommendations for Women < 65 years old.(n=539) living in lower-income census tracts of Washington, D.C. 2000.

Significant Factors	Pap Test	Clinical Breast Exam	Mammogram	FOBT[©]
Adherence to Screening- Adjusted OR[†] (95% CI)				
PATIENT CHARACTERISTICS:				
Knowledge/Attitudes/Beliefs [Ψ]				
Avoid Doctor Even if Sick		0.56* (0.34-0.91)	0.61* (0.37-1.00)	
Demographic & Socioeconomic				
Age (50-64 vs. the 40-49 reference group)			2.14** (1.43-3.20)	
Income Higher (vs. lower, reference group)	3.10**(1.59-5.98)		1.78* (1.10-3.16)	
Owns Home (vs. rents, reference group)	1.95* (1.12-3.41)			
Education Higher (vs. lower reference group)		2.0** (1.16-3.52)	2.68** (1.58-4.58)	
African-American (vs. Caucasian reference)				3.15**(1.37-7.21)
PRIMARY CARE ATTAINMENT:				
Visit Continuity				
No Usual Source of Care (USOC)	0.42 (0.12-1.45)	0.19** (0.05-0.69)	0.24* (0.06-0.96)	
USOC (has a place only) (Reference Group)	REF	REF	REF	
USOC and Reg Doc, but Doesn't See all visits	2.66** (1.29-5.52)	1.30 (0.67-2.23)	1.49 (0.82-2.71)	
USOC and Reg Doc; Does See for all visits	3.54** (1.69-7.40)	1.82* (1.10-3.28)	2.10** (1.17-3.74)	
Comprehensiveness—All needs met Lower		REF		
Higher		0.43* (0.19-0.98)		
Comprehensiveness—Counseling Lower	REF	REF		
Higher	2.70** (1.50-4.83)	2.17** (1.21-3.88)		
Patient Physician Relationship—Compassion Lower				REF
Higher				2.91*(1.10-7.78)
Patient Physician Relationship-Trust Lower	REF			
Higher	3.11** (1.30-7.43)			
HEALTH INSURANCE AND PLAN TYPE:				
Uninsured			REF	REF
Public Only			0.63 (0.31-1.28)	2.24 (0.64-7.89)
Private HMO			2.29**(1.14-4.57)	6.39**(2.05-19.90)
Private Non-HMO			1.00 (0.54-1.86)	2.22 (0.73-6.78)

[Ψ] Reference group is the absence of this belief or attitude   **=p≤.01   *p<.05

[†] All odds ratios are adjusted for attitudes, beliefs, knowledge regarding cancer, insurance, age, income, home ownership, education, race/ethnicity, marital and health status, all features of primary care: continuity, accessibility, comprehensiveness, coordination and the patient-provider relationship (compassion, communication and trust aspects), and insurance and health plan type.

[©] FOBT Adherence only applies to women over age 52.

Table 4. Factors Significantly Associated with Adherence to Cancer Screening Recommendations for Women ≥ 65 Years Old (n=666) living in low-income census tracts of Washington, D.C. 2000.

| | Adherence to Screening OR[†] (95% CI) | | | |
Significant Factors	Pap Test	Clinical Breast Exam	Mammogram	FOBT[©]
PATIENT CHARACTERISTICS:				
Knowledge/Attitudes/Beliefs [ψ]				
Surgery Causes Faster Growth	0.59**(0.40-0.86)			
Prayer Alone Heals Cancer		0.67*(0.47-0.95)		
Demographic & Socioeconomic				
Income (higher vs. lowest reference group)				
Owns home (vs. Rents reference group)		1.61**(1.10-2.34)	1.58*(1.09-2.31)	
Education (higher vs. lower ref group)			1.48*(1.02-2.17)	1.64* (1.02-2.64)
Marital Status (vs. single ref group)	1.60* (1.02-2.49)			
PRIMARY CARE ATTAINMENT:				
Visit Continuity				
No Usual Source of Care (USOC)	0.32*(0.14-0.93)	0.19**(0.05-0.68)	0.34 (0.13-0.90)	
USOC (has a place only) (Reference group)	REF	REF	REF	
USOC and Reg Doc, but Doesn't See all visits	0.94 (0.50-1.74)	0.97 (0.54-1.76)	1.38 (0.76-2.49)	
USOC and Reg Doc; Does See for all visits	0.76 (0.42-1.38)	1.22 (0.69-2.16)	1.38 (0.78-2.42)	
Comprehensiveness—Counseling Lower	REF	REF	REF	REF
Higher	1.68* (1.01-2.82)	1.46*(1.01-2.12)	1.53**(1.09-2.15)	1.90 **(1.15-3.13)
Patient Physician Relationship-Communication				
Lower	REF			
Higher	2.37**(1.31-4.28)			
Coordination – of Specialist Care Low		REF	REF	REF
(N=748) Mid		1.47* (1.00-2.17)	1.63* (1.09-2.44)	1.27 (0.84-1.93)
High		2.36**(1.44-3.87)	1.78**(1.11-2.85)	1.78**(1.13-2.82)
HEALTH INSURANCE AND PLAN TYPE:				
Uninsured	1.37 (0.66-2.87)	1.75 (0.83-3.71)	1.15 (0.56-2.35)	0.68 (0.28-1.69)
Original Medicare (may have Medicaid too)*	REF	REF	REF	REF
Medicare Managed Care	1.89** (1.11-3.17)	2.04** (1.21-3.44)	1.95** (1.15-3.31)	1.70* (1.01-2.83)
Medicare plus Private Medigap	1.53 (1.00-2.31)	0.89 (0.60-1.32)	1.25 (0.83-1.87)	1.15 (0.75-1.77)

[ψ] Reference group is the absence of this belief or attitude   **=p≤.01   *p<.05

[†] All odds ratios are adjusted for attitudes, beliefs, knowledge regarding cancer, insurance, age, SES: income, home ownership, education, race/ethnicity, marital and health status, all features of primary care: continuity, accessibility, comprehensiveness, coordination and the patient-provider relationship (compassion, communication and trust aspects), and insurance and health plan type.

Appendix: Brief Summary of the Items Measuring Primary Care Features:

CONTINUITY OF CARE
Continuity of visits with a Single Provider$^\psi$
▪ Is there one particular <u>place</u> that you go to if you are sick or need advice about your health?
▪ Is there a place where you go <u>most often</u> if you are sick or need advice about your health?
▪ Do you have one person you think of as your <u>regular personal doctor or nurse?</u>
▪ When you go for a <u>check-up or routine care, how often do you see your regular doctor</u> as opposed to an assistant or partner?
▪ When you are <u>sick</u> and go to the doctor, how <u>often do you see your regular doctor</u> as opposed to an assistant or partner?
Length of Relationship with a Single Provider
▪ How long has this person/place been your doctor/source of care?
ACCESSIBILITY
Accessibility—Geographic
▪ How would you rate the convenience of your regular doctor/nurse's office location?
Accessibility—Organizational
▪ How would you rate the hours that your doctor/nurse/place is open for medical appointments?…Is it poor, fair, good, excellent?
▪ How would you rate the usual wait for an appointment when you are sick and call the office asking to be seen?…
▪ How would you rate the <u>ability to get through</u> to the doctor's office by phone?…
▪ How would you rate amount of <u>time</u> your regular doctor/nurse/place spends with you?…
Accessibility—Financial
▪ Considering the amount of money you pay for visits, would you say it is….extremely high, somewhat high, about right or low?
COMPREHENSIVENESS:
General Comprehensiveness, i.e. All Needs Met:
▪ Thinking about how well your doctor knows you, how would you rate your doctor/nurse's ability to take care of all of your health care needs? Would you say it is poor, fair, good or excellent?
Counseling:
▪ Have you <u>smoked</u> in the past 3 years? (Yes/No)
▪ Has your regular doctor <u>talked</u> with you about <u>smoking</u> in the past year? (asked of recent smokers)
▪ Has your regular doc talked with you about <u>alcohol/drinking</u> in past year?
▪ Has your regular doc talked with you about <u>diet</u> in the past year?
COORDINATION OF SPECIALTY CARE
Has your doctor ever recommended that you see a specialist for a specific health problem? IF YES THEN Thinking about the times your doctor has recommended you see a specialist, how would you rate: (Poor, Fair, Good, Excellent)
▪ The help your regular doctor/nurse/place gave you in getting an appointment for specialty care you needed?
▪ Regular doctor's involvement in your care when treated by a specialist or when hospitalized?
▪ The help your regular doctor gave you in understanding what the specialist or other doctor said about you?
PATIENT-PROVIDER RELATIONSHIP:
Communication :
▪ How would you rate the doctor's <u>explanations</u> of health problems or treatment? (Poor, Fair, Good, Excellent)
Compassion :
▪ How would you rate the doctor's <u>patience</u> with your questions or worries? (Poor, Fair, Good, Excellent)
▪ How would you rate the doctor's <u>caring and concern</u> for you?
▪ How would you rate the doctor's <u>respect</u> for you?
Trust:
▪ All things considered, how much do you trust your doctor? (Scale of 0-10 Where 0 is "Not at all" and 10 is "Completely."

$^\psi$ Creation of the Visit Continuity variable and the item responses used are detailed in the Methods section.

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27

Are We Getting the Message Out to All?
Health Information Sources and Ethnicity

Ann S. O'Malley, MD, MPH, Jon F. Kerner, PhD, Lenora Johnson, MPH, CHES

Background: Over 80% of the excess deaths in minority and economically disadvantaged populations are from diseases with preventable or controllable contributing factors. However, mainstream health education targeting behavior change often fails to reach minority populations.

Objective: To identify the health and cancer information sources used by a multi-ethnic population and to determine whether information sources differ by ethnic group, age, gender, and socioeconomic status.

Methods: A multilingual, random-digit dial telephone survey of 2462 Hispanic (Colombian, Dominican, Ecuadorian, and Puerto Rican) and black (Caribbean, Haitian, and U.S.-born) persons, aged 18–80 years, from a population-based quota sample, New York City, 1992.

Results: All ethnic and age groups cited a health professional as the most common source of health information (40% overall). The next most commonly cited sources overall were: television (21%), hospitals or doctor's offices (18%), books (17%), magazines (15%), brochures/pamphlets (11%), and radio (8%). Responses on sources of cancer information followed a similar pattern. Black subgroups were all significantly more likely than Hispanic subgroups to get their health information from a doctor or other health professional ($p = 0.001$). Use of the radio as a source of health information was highest among Haitians (20.8%) and Colombians (12.5%), and lowest among U.S.-born blacks (4.2%) ($p = 0.001$), but there was no difference in the use of television. Among immigrants, as the proportion of life spent in mainland U.S. rose, increasing percentages cited magazines ($p = 0.001$) and decreasing percentages cited radio ($p = 0.025$) as a health information source. Less educated persons and more recent immigrants were most likely to report inability to get health information ($p = 0.001$).

Conclusions: Given the variation in sources of health and cancer information, identification of those most commonly used is important to health educators' and public health practitioners' efforts to target hard-to-reach ethnic minorities.

Medical Subject Headings (MeSH): information dissemination, health behavior, ethnicity, Hispanic Americans, information distribution, communication (Am J Prev Med 1999; 17(3):198–202) © 1999 American Journal of Preventive Medicine

Introduction

Minority and economically disadvantaged communities lag behind the U.S. population overall on virtually all indicators of health status. Over 80% of excess deaths in these populations are from diseases with preventable or controllable contributing factors: cancer, heart disease and stroke, homicide and unintentional injuries, infant mortality, diabetes, and chemical (primarily alcohol) abuse.[1] However,

mainstream health education targeting behavior change often fails to reach minority populations.[1-3]

While some data on the health information sources used by the majority population have been published,[4-6] little information is available on the sources of health information used most often by persons of color, especially within northeastern Hispanic and black communities. Prior work comparing non-Hispanic whites and southwestern Hispanics has shown ethnic-specific preferences for certain sources of health information.[7-9]

In addition, most studies on information sources focus on patients currently undergoing treatment for a specific disease[10] rather than on the general asymptomatic population.

The purpose of this report is (1) to identify the health information sources used by the ethnic groups

From the Division of General Internal Medicine, Clinical Economics Research Unit (O'Malley) and the Division of Cancer Prevention and Control, Lombardi Cancer Center (Kerner, Johnson), Georgetown University Medical Center, Washington, DC

Address correspondence and reprint requests to: Ann S. O'Malley, MD, MPH, 2233 Wisconsin Avenue, NW, Suite 440, Washington, DC 20007. E-mail: omalleya@gunet.georgetown.edu.

accounting for the largest percentage of blacks and Hispanics in New York City and (2) to assess how ethnicity, age, gender, language, and socioeconomic status relate to differences in health information sources used.

Methods

This study is part of a larger project assessing the general health and cancer-prevention needs of Caribbean, Haitian, and U.S.-born blacks, and Puerto Rican, Dominican, Colombian, and Ecuadorian Hispanics living in all 5 boroughs of New York City. These 7 populations compose the largest subgroups of blacks and Hispanics in New York City.[11] The majority (75%) of the sample were immigrants. Data were collected from May to October of 1992 by experienced multilingual interviewers using computer-assisted telephone interviews (CATI). The study used a quota sample to identify 50 men and 50 women from each racial/ethnic group (except for Haitians; $n = 25$ per group because they were added after grant funding) in 4 age groups: 18–44 years, 45–54 years, 55–64 years, and 65–74 years for a total goal of 2600. Details on the survey and sampling methodology have been published elsewhere.[12,13]

Survey participants were asked in their language of preference (English, Spanish, or Creole) a previously validated,[14] open-ended question: "Where do you usually get your health information?" Interviewers had a long list of potential responses that could be checked if offered by the respondent. The potential responses included:

People: (doctor/health professional [i.e., clinician], family, friend, home country, other);

Cancer organizations/programs: (Cancer information services, National Cancer Institute, American Cancer Society (ACS), Telephone information—Public service or hot line, government agencies/program—unspecified, private organization/program—unspecified, other cancer organization/program—unspecified, health fairs/seminars);

Non-cancer organizations/places: (church/religious place, grocery store, hospital/doctor's office, school, library, workplace, union, other local organization, other national organization, HMO/GHI/HIP-Insurance company);

Electronic media: (radio, television [TV]);

Printed Material: (brochure/pamphlet, book, magazine, newspaper, medical journal, encyclopedia, other);

Other: (specify); and

Unable to get information; None/Never looked/Don't know.

Of those who responded positively to another item on whether they had sought cancer information in the past 5 years, a further question was asked, "When you were

seeking cancer information, where did you get it?" Potential responses that the interviewer could check, if offered by the respondent, were the same as above.

We report descriptive statistics on sources of health information used by black and Hispanic ethnic subgroups stratified by personal, demographic,[13,15,16] and socioeconomic characteristics. Stratified analyses and multivariate logistic regressions were done, using SAS (SAS Software, Cary, NC),[17] to assess whether use of clinician as information source (the most commonly cited response) differed significantly by ethnicity after controlling for insurance status, proportion of life on mainland U.S., and presence of a usual source of care.

Results

The survey was completed by 2462 persons. The response rate for all calls made, including those to determine eligibility, was 62.3%. Among respondents qualifying for the survey on the basis of age and ethnicity, the refusal rate was 2.1%.

Health Information Sources Cited by the Overall Sample

For all ethnic and age groups the highest proportion of respondents (31%–63%) volunteered that a doctor or health professional was a source of health information. The next most commonly cited sources of health information for the overall sample were: television (21%), hospitals or doctor's offices (18%), books (17%), magazines (15%), brochures/pamphlets (11%), and radio (8%). Differences by ethnicity are summarized in Table 1.

Cancer Information Sources for the Overall Sample

Among the 1333 respondents (54% of the total sample) who had sought cancer information in the previous 5 years, the proportions using each type of cancer information source followed a similar pattern to the responses about health information in general (clinician 22%; hospital/doctor's office 15%; radio 6.1%; television 18.7%; brochure 16.8%; book 13.1%; magazine 15.2%; newspaper 9.3%). Cancer organizations/programs (CIS, NCI, ACS) were cited by ≤1% of respondents as sources from which cancer information was sought. Mention of the workplace (2.5%), schools (2.2%), churches/religious places (1%), libraries (1%), cancer organizations/programs (<1%), unions (<1%), insurance companies (<1%), home country (<1%), or grocery stores (<0.1%) as either a general health or a cancer information source was universally low.

Table 1. Health information source reported by ethnic groups, multi-ethnic sample, New York City, 1992*

Source of Information	Total N = 2462 %	Colombian n = 329 %	Dominican n = 492 %	Ecuadorian n = 258 %	Puerto Rican n = 450 %	Caribbean n = 357 %	Haitian n = 168 %	U.S.-born Black n = 408 %	p
People									
Doctor/Health-Prof.	40.0	34.0	31.1	32.9	36.2	48.2	63.7	47.6	.001
Family	4.2	3.3	3.6	2.7	4.7	5.3	4.7	4.7	.664
Friend	3.9	2.7	3.7	1.5	4.7	4.8	4.8	4.9	.252
Non-Cancer Organizations/Places									
Hospital/Dr.'s Office	18.4	21.0	22.2	19.4	20.7	12.0	13.1	16.4	.001
School	2.2	2.7	2.6	2.7	0.7	2.0	5.4	1.2	.013
Workplace	2.5	0.3	2.2	1.6	2.7	5.0	2.4	2.7	.008
Electronic Media									
Radio	8.1	12.5	8.3	6.2	7.1	4.7	20.8	4.2	.001
Television	21.1	23.1	19.9	18.6	19.1	21.0	30.4	21.6	.065
Printed Material									
Brochure/Pamphlet	10.7	11.6	8.7	6.7	12.0	9.8	16.1	12.2	.030
Book	17.2	13.4	11.2	12.0	15.8	26.0	19.0	23.8	.001
Magazine	15.3	14.9	11.4	9.7	17.6	17.7	11.9	20.6	.001
Newspaper	9.5	6.1	9.6	6.6	10.7	9.5	8.3	13.0	.032
Medical Journal	4.8	0.9	3.0	3.1	3.8	8.7	5.4	8.8	.001
Other									
Unable to get info.	2.8	3.6	4.7	5.0	1.1	2.2	4.8	0.0	.001
None/Never looked	3.7	4.9	6.1	3.5	4.4	2.2	3.0	1.0	.002

*Only information sources reported by ≥2% of the sample are listed in this table. (N = 2462) (Responses to open-ended question, "Where do you usually get your health information?")

Role of Social and Demographic Factors on use of Health Information Sources

Age. There was a linear increase in percentage citing the doctor/health professional as a source of health information with increasing age (18–44 years: 33.3%; 45–54 years: 38.2%; 55–64 years: 44.2%; 65 + years: 52.1% $p = 0.001$). There was a decrease in reports of use of television as an information source with increasing age ($p = 0.001$). Citing magazines or newspapers as a health information source was higher in the two younger age groups (19.3% and 11.2%, respectively) and decreased in the older age groups (10.8% and 6.3%: $p = 0.001$ and $p = 0.033$, respectively) (data not shown).

Gender. For all ethnic groups combined, females were more likely than males to get their health information from a doctor/health professional (42.5% versus 36.7%; $p = 0.003$). Males were more likely than females to get their health information from newspapers (12.9% versus 7.0%; $p = 0.001$, respectively). Similar and significant differences were found by gender for sources of cancer information (data not shown).

Educational and immigration status. Increasing education was negatively associated with citing hospitals as a source of health information. ($p = 0.002$) Television was cited as an information source among a larger percentage of more highly educated persons (high school graduates or higher) (24.3%) than less educated persons (8 years or less) (14.9%) ($p = 0.001$). Also, less

educated persons and more recent immigrants were more likely to report being unable to get health information ($p = 0.001$). As proportion of life spent in the mainland U.S. increased, higher percentages cited magazines as a source of health information ($p = 0.001$) and conversely, lower proportions cited radio as a source of health information ($p = 0.025$) (data not shown).

Insurance. Since insurance is the most powerful predictor of access to the health care system, it was not surprising that the highest proportion of persons saying that they usually get their health information from a doctor/health professional was privately insured (55.4% private, 28.0% public, and 16.5% uninsured $p = 0.001$). Among the insured, similar proportions cited the doctor/health professional as a usual source of health information (45.2% for private and 42.8% for public); whereas only 27.9% of uninsured persons cited the doctor/health professional as a usual information source ($p = 0.001$). Use of print materials as information sources (brochures/pamphlets, books, magazines, and newspaper) was highest among the privately insured (data not shown).

Ethnicity. When the Hispanic groups' use of television as a health information source was stratified by a language-based acculturation measure, ethnic differences did emerge. Among less acculturated Hispanics (those who used Spanish more than English with family, friends, co-workers, and in media consump-

tion), 23% of Colombians, 18% of Dominicans, 19% of Ecuadorians versus only 11% of Puerto Ricans reported using TV as a source of health information ($p = 0.04$). Among the more acculturated Hispanic groups, there were no significant differences in TV use. For all other forms of media there were no significant ethnic differences within each mode's use as health information source when stratified by acculturation (data not shown).

Multivariate logistic regression models, in which use of a clinician as information source was the dependent variable, were done to assess whether ethnic subgroup was a significant predictor after controlling for insurance status, proportion of life in the U.S., and presence of a usual source of care.[12,13,18] Compared to U.S.-born blacks (reference group), Dominicans and Puerto Ricans were significantly less likely (OR = 0.731, 95% CI: 0.55–0.96; OR = 0.742, 95% CI: 0.57–0.96, respectively) and Caribbeans and Haitians were significantly more likely (OR = 1.44, 95% CI:1.1–1.9; OR = 3.0, 95% CI:2.1–4.4, respectively) to use a clinician as information source. Thus, ethnic subgroup, insurance, and presence of a usual source of care remained significant predictors of the use of a clinician as a health information source (data not shown).

Conclusions

This study found wide variation by ethnicity, age, gender, socioeconomic status, insurance, and the proportion of life spent in the U.S. in the reported sources of health and cancer information.

In research on the perceived credibility[7] and frequency [10,19–21] of information sources among Mexican-American Hispanics and non-Hispanics whites, physicians were reported as most credible and most frequently used.[7,10,19–21] Given good evidence that clinicians can change some patient behaviors through simple counseling interventions in the primary care setting,[21–24] it is reassuring to find that this was the usual source of health information cited by the largest percentage of respondents. This also highlights the importance of patient-provider communication in information dissemination to higher-risk groups.

In terms of comparisons between the non-Hispanic white population and persons of color, National Health Interview Survey data indicate that African Americans are more likely than whites to receive some types of health information (e.g., HIV information) by reading brochures or listening to the radio.[25] In other studies of HIV information, urban African Americans and Hispanics were more likely to rely on mass media sources (e.g., television) whereas whites were more likely to receive information through targeted small media (e.g., brochures),[26] newspapers, or magazines.[27] Use of English print media is likely related to language preference and acculturation level. In this study, respon-

dents were not asked to specify whether the forms of print media used were in English or Spanish, so associations between language skills and media language consumption could not be ascertained.

Health communication efforts through mass media have been shown to be most effective when combined with community-based programs.[28] In this study, less educated (≤ 8 years of school) and less acculturated persons had difficulty obtaining health information. This difficulty may have been due to low literacy levels, poorer access to media and health professionals, preoccupation among recent immigrants with socioeconomic survival, or lack of knowledge of where to go for health information. Traditional media sources may be less promising avenues for reaching higher-risk persons. More grassroots community-based efforts (e.g., use of lay health workers or targeting barrios) may be necessary to effectively target these groups.

There is too little literature on health information sources in minority groups to verify whether changes in information campaigns have occurred since these data were collected. At the very least, these data serve as a baseline of health information sources used in this multi-ethnic community, and can help inform strategies to target these populations. One source of information used with increasing frequency since 1992 is the Internet; however, its accessibility to this population is unclear. Other methodologic limitations in these data have been described elsewhere.[12,13]

This study described health information sources used by hard-to-reach members of these ethnic groups. Further study of the effectiveness of these information sources in promoting behavior change in these communities is needed. Given that these hard-to-reach populations have rates of preventable deaths in excess of the majority population, renewed efforts to provide culturally appropriate and educationally tailored messages and materials to these populations must be given serious consideration.

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Acculturation and Breast Cancer Screening Among Hispanic Women in New York City

Ann S. O'Malley, MD, MPH, Jon Kerner, PhD, Ayah E. Johnson, PhD, and Jeanne Mandelblatt, MD, MPH

A B S T R A C T

Objectives. This study investigated whether acculturation was associated with the receipt of clinical breast examinations and mammograms among Colombian, Ecuadorian, Dominican, and Puerto Rican women aged 18 to 74 years in New York City in 1992.

Methods. A bilingual, targeted, random-digit-dialed telephone survey was conducted among 908 Hispanic women from a population-based quota sample. Outcome measures included ever and recent use of clinical breast examinations and mammograms. Multivariate logistic regression models were used to assess the effect of acculturation on screening use.

Results. When demographic, socioeconomic, and health system characteristics and cancer attitudes and beliefs were controlled for, women who were more acculturated had significantly higher odds of ever and recently receiving a clinical breast examination ($P \leq .01$) and of ever ($P \leq .01$) and recently ($P \leq .05$) receiving a mammogram than did less acculturated women. For all screening measures, there was a linear increase in the adjusted probability of being screened as a function of acculturation.

Conclusions. Neighborhood and health system interventions to increase screening among Hispanic women should target the less acculturated. (*Am J Public Health.* 1999;89:219–227)

Despite the fact that Hispanic women have lower incidence rates for breast cancer than White non-Hispanic women, Hispanic women who do develop breast cancer are more likely to die of the disease.[1–6] This mortality differential is, in part, related to Hispanics' being diagnosed at a later stage of breast cancer than White non-Hispanics, even after adjustment for socioeconomic status and duration of symptoms.[2,7,8] This stage differential is likely related to differential screening use.[6,9–11]

Socioeconomic status and having health insurance, having a usual source of care, and having a physician's recommendation for screening all predict screening use in both non-Hispanic and Hispanic women.[11–16] Another factor that may influence breast cancer screening use by Hispanics is acculturation.[17–22] Acculturation has been defined as "the psychosocial adaptation of persons from their culture of origin to a new or host cultural environment."[23(p90)] For immigrants from non-English–speaking countries, acculturation includes the choice of language for use in daily life.[24]

Previous studies of the role of acculturation in breast cancer screening have largely focused on Hispanics as a whole, and these studies have had mixed findings.[17–21] When ethnic subgroups have been identified, the focus has been on Mexican Americans, and to a lesser extent on Cubans and Puerto Ricans, in California and the Southwest.[17–21] The ethnic composition of New York City's Hispanic population (1 737 927 persons) differs from that of the southwestern United States; in 1990, the 4 largest Hispanic subgroups in New York City were Puerto Rican (49.5%), Dominican (19.1%), Colombian (5%), and Ecuadorian (4.5%).[25] The issue of acculturation and breast cancer screening among these northeastern Hispanics has received little attention. The purpose of this study was to assess the extent to which acculturation plays a role in the use of recommended clinical breast examinations and mammograms in these 4 groups.

Methods

Survey Design and Sampling

This study was part of a larger study of cancer prevention and control needs of Caribbean-, Haitian-, and US-born Blacks and Puerto Rican, Dominican, Colombian, and Ecuadorian Hispanics living in New York City in 1992.[15,26] The 4 Hispanic subgroups in the larger study comprised 908 women, who are the focus of this study. These 4 subgroups constituted the largest subgroups of Hispanics in New York City according to census data available at the time of the survey.[25,27]

In the present study we used a quota sample to identify 50 women from each of 4 age groups—18 to 44 years, 45 to 54 years, 55 to 64 years, and 65 to 74 years—in each of 4 Hispanic groups, for an initial goal of 800 women. Because of an administrative oversight unrelated to sample characteristics, Dominicans aged 18 to 44 years were inadvertently oversampled. Since the quota sample was chosen to provide groups

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with similar age distributions, it allowed the acquisition of adequate numbers of respondents of all ages for each ethnic group.[28]

A comparison of this quota sample's characteristics with those of an area probability sample, the sample of the Census Bureau's Current Population Survey during the same time period, suggests that our sample is comparable to the weighted probability sample of New York City Hispanics on several demographic parameters unrelated to the quota sampling framework.[29]

The study sample was selected from the telephone exchanges for all 5 boroughs of New York City. Both list and random-digit-dialed sampling techniques were used to ensure coverage of households with unlisted numbers and members of the 4 ethnic groups. Targeting procedures employing census data, zip codes, and telephone exchanges were used to locate low-count ethnic groups clustering in specific neighborhoods.

Data Collection

Community leaders reflecting the cultural backgrounds of the study population were extensively involved in the study design and survey promotion. The instrument was developed with existing national survey items[20,30–36] and modified for use in the target populations. New items were also designed and validated. The survey content areas were then reviewed by focus groups and community advisors from the ethnic communities. Spanish versions of the survey were pilot tested and were validated through standard translation and back-translation. Respondents could choose to be interviewed in Spanish or English. All data were collected via computer-assisted telephone interview from May to October 1992.

Dependent Variables

Use of clinical breast examinations and use of mammograms were the outcome measures. Two dichotomous variables were used for each screening procedure. The first variable was whether the respondent had ever had the procedure. She was asked, "Have you ever had a mammogram?" and "Have you ever had a breast physical exam by a doctor, nurse, or medical assistant?" The respondent was given definitions of the procedures before being asked about use.

The second dichotomous variable was whether the woman had recently been screened. She was asked, "When did you have your last mammogram?" and "About how long has it been since you had a breast physical exam by a doctor, nurse, or medical assistant [≤1, 1–2, 2–3, or >3 years]?"

TABLE 1—Characteristics of the Sample of Hispanic Women (n = 908) in a Study of Cancer Prevention and Control Needs: New York City, 1992

	Ethnicity, %				
	Colombian (n = 202)	Dominican (n = 308)	Ecuadorian (n = 151)	Puerto Rican (n = 247)	P
Age, y					
18–44	31.2	50.7	34.4	37.3	
45–54	24.7	16.6	32.5	20.7	
55–64	25.3	16.6	22.5	21.1	
≥65	18.8	16.2	10.6	21.1	.001
Education					
<12 y	40.6	51.6	45.7	46.1	
12–15 y	45.5	37.6	46.4	40.9	
College graduate	13.9	10.7	7.9	13.0	.161
Marital status					
Married	45.5	41.2	53.0	36.4	
Single	54.5	58.7	45.7	62.7	.008
Household income, $					
<20 000	38.6	49.0	37.1	35.2	
≥20 000	26.2	22.4	25.2	38.1	
Missing[a]	35.1	28.6	37.6	26.7	.001
Health status					
Excellent–very good	32.7	33.1	37.1	32.8	
Good	33.2	23.4	28.5	32.0	
Fair–poor	30.2	39.6	33.8	31.6	.321
Age at immigration, y					
≤16	9.4	18.2	7.3	53.9	
>16	90.6	81.8	92.7	46.1	.001
Interview language					
English	9.4	14.0	8.6	42.1	
Spanish	90.6	86.0	91.4	57.9	.001
Acculturation					
Lower	75.7	76.9	77.5	37.8	
Higher	24.3	23.1	22.5	62.2	.001
Employment status					
Unpaid	43.1	52.6	36.4	39.3	
Retired	12.9	15.3	15.9	17.8	
Part-time	14.4	5.2	7.3	6.9	
Full-time	29.2	26.3	39.1	35.2	.001
Insurance status					
Uninsured	35.6	26.0	36.4	8.1	
Medicaid/Medicare only	22.8	43.2	27.8	40.5	
Private	39.1	28.6	33.1	49.0	.001
Has a usual source of care	80.7	80.5	82.8	90.7	.006

[a]Income was missing for women who refused to answer the question or answered "Don't know."

"Recent" was defined according to 1992 American Cancer Society (ACS) guidelines for routine screening[37]: for clinical breast examination, every year for women older than 40 years and every 3 years or less for women aged 20 to 40 years, and for mammogram, every 2 years or less for women aged 45 years and older. Women aged 40 to 44 years were excluded from mammogram analyses because of the quota sample structure. An age-related screening "rigor" variable was also included, reflecting the fact that the quota ages included groups of women for whom recommended screening intervals differed.

Independent Variables

Since language is an important component of modifiable aspects of the process[38,39] of breast cancer screening, we chose to focus on linguistic aspects of acculturation. Other indicators of acculturation (recency of immigration, proportion of life spent in mainland US, age at immigration, whether respondent was first or second generation, and language of interview) were available; however, these were not included in our acculturation scale or multivariate models because they were highly correlated and displayed strong multicollinearity with the acculturation scale.[40]

TABLE 2—Selected Characteristics (%) of the Sample of Hispanic Women (n = 907[a]), by Acculturation Level: New York City, 1992

| | Acculturation | | |
	Lower (n = 307)	Higher (n = 600)	P
Age, y			
18–44 (n = 362)	32.0	55.4	
45–54 (n = 201)	23.2	20.2	
55–64 (n = 188)	23.5	15.3	
≥65 (n = 156)	21.3	9.1	.001
Education, y			
<12 (n = 424)	58.8	23.1	
12–15 (n = 379)	33.2	58.6	
≥16 (n = 104)	8.0	18.3	.001
Household income, $			
<20 000	46.7	30.0	
≥20 000	16.0	51.1	
Missing[b]	37.3	18.9	.001
Usual site of care			
Private doctor's office	39.4	45.4	
Hospital outpatient department	15.6	14.8	
Public health clinic	8.1	6.3	
HMO	10.8	8.6	
Emergency room	8.9	9.5	
No usual site	17.1	15.4	.525
Insurance status			
Private insurance (n = 337)	25.3	60.3	
Only Medicare or Medicaid (n = 321)	41.7	23.1	
Uninsured (n = 227)	30.2	15.0	.001
Proportion of life spent in mainland US, %			
<25 (n = 343)	37.5	9.9	
26–50 (n = 317)	43.2	20.2	
51–75 (n = 181)	16.4	27.8	
>75 (n = 53)	2.8	42.1	.001
Age at immigration, y			
≤16 (n = 218)	8.3	54.7	
>16 (n = 689)	91.7	45.3	.001

[a]In some categories, n's may not add up to 907 because some women refused to answer the question or answered "Don't know." There were no significant differences between the numbers of women with higher and lower acculturation scores in the "don't know/refused" category for any variable except income.

[b]Income was missing for women who refused to answer the question or answered "Don't know."

Our acculturation measure was a continuous variable based on a 12-item scale (available from the authors). These items were drawn from a 26-item acculturation scale developed by Burnam et al.[23] and later validated, in this shortened form, in a New York City Hispanic population by Epstein et al.[24] This scale was reliable in our sample (Cronbach α = .93). The 12 items asked about language and media (television, radio, books, magazines, newspapers) use in a variety of situations (work, home, neighborhood, shopping) and with different people (including spouses or partners, children, parents, and friends). For each item, the 5 response options were as follows: 1 = only Spanish, 2 = mostly Spanish, 3 = Spanish and English, 4 = mostly English, and 5 = only English. Acculturation level was calculated as a mean score of these 12 items (1 = least accultur-ated, 5 = most acculturated).[23] (For ease of understanding, in Tables 1–3 the acculturation score is dichotomized into "lower" [score ≤ 2.5] and "higher" [score > 2.5]. In Table 4 [multivariate models], the acculturation score is continuous.)

Controlling variables included sociodemographics (age, education, marital status, income, employment); health status (self-assessed 5-item measure, ranging from "poor" to "excellent"); site of care; presence of a usual source of care; insurance status (uninsured, public insurance only [i.e., Medicare or Medicaid], or private insurance); and cancer attitudes and beliefs.[8,11,41–48] Since approximately 30% of the respondents refused to provide data on income, this variable was included in the multivariate analyses by keeping the refusals as a separate dummy variable.

Cancer attitudes were measured with the Cancer Attitudes Scale.[26,49] This scale includes an anxiety subscale (6 items, Kuder-Richardson–20 = 0.57) and a hopelessness subscale (8 items, Kuder-Richardson–20 = 0.65). Perceived risk for developing cancer was measured with 2 items ($r = 0.70$) and concern about cancer was measured with 2 items ($r = 0.72$).[26]

Analysis

Bivariate analyses were performed to assess relationships among categorical variables. Statistical significance in cross-tabulations was evaluated with the χ^2 statistic. We tested for interactions between acculturation (dichotomized) and several potential effect modifiers with respect to screening use: education, insurance status, income, and health status.[47] For women who chose to do the interview in Spanish, an additional test for interaction between acculturation and language of the health care provider was performed. No significant interactions were found between acculturation and income, insurance status, or health status in predicting screening use. There was a tendency for education to modify acculturation's effect on screening; however, estimates for these interaction terms were highly unstable in the multivariate logistic regressions and were not included in the final models.

Stepwise logistic regression models assessed the effect of acculturation and controlling variables on each of the cancer screening outcomes. Variables that had at least 1 significant dummy (α level for stepwise regression = .20) were included in the final model. All models exhibited goodness of fit by the Hosmer-Lemeshow test.[50]

The parameter estimates from the final multivariate logistic regression models were then entered into the logit function to calculate the adjusted probabilities of screening for each of the 5 levels of acculturation.[51] An additional model was created for the subgroup of women who completed the interview in Spanish (n = 726). This model was the same as the overall final logistic regression model for the entire group (n = 907), with the addition (one at a time) of variables on language and its importance in the health care setting (whether the physician spoke Spanish, importance of physician's speaking Spanish, importance of someone in the clinic's speaking Spanish). All analyses were performed with SAS.[52]

Results

A total of 908 Hispanic women completed the survey. The overall response rate

TABLE 3—Percentage (Unadjusted) of Hispanic Women Receiving Breast Cancer Screening, by Selected Characteristics: New York City, 1992

	Clinical Breast Examination		Mammography	
	Ever (n = 888)	Recent[a] (n = 882)	Ever (n = 542)	Recent[a] (n = 524)
Total sample	86.3	68.1	71.6	62.0
Demographic characteristics				
Age, y				
18–44	85.3	77.8	. . .[b]	. . .[b]
45–54	85.1	59.2	66.7	58.5
55–64	90.9	68.5	74.7	66.5
≥65	84.5	58.1**	74.2	61.2
Ethnicity				
Colombian	87.9	66.3	73.4	62.7
Dominican	80.5	64.7	66.9	53.4
Ecuadorian	85.3	69.6	68.4	62.5
Puerto Rican	92.6**	72.9	76.6	69.9*
Marital status				
Married	86.1	70.0	68.2	61.3
Single, divorced, widowed	86.5	66.7	73.6	62.2*
Socioeconomic characteristics				
Education				
<12 y	83.2	59.2	69.3	59.3
12–15 y	88.0	74.4	73.7	66.3
College graduate	92.4*	81.7**	78.0	65.8
Household income, $				
<20 000	83.9	63.9	68.6	60.2
≥20 000	92.0	81.8	78.4	77.6
Missing[c]	84.2**	61.3**	71.1	55.7**
Employment status				
Unpaid	87.8	65.4	69.3	59.2
Retired	84.1	61.2	75.5	61.9
Part-time	87.5	70.4	67.4	61.9
Full-time	88.6	74.8*	72.5	66.4
Insurance status				
Uninsured	77.5	53.4	53.4	45.4
Medicaid/Medicare only	88.2	68.0	77.5	63.7
Private	91.0**	78.3**	76.3	70.3**

(Continued)

The mean adjusted probabilities of screening as a function of acculturation are shown in Figure 1. For all tests, there is a linear increase in the adjusted probability of screening as one goes from least to most acculturated.

Of the 908 women interviewed, 726 chose to be interviewed in Spanish. These women were asked whether the doctor at their usual site of care spoke Spanish and about the importance of either their doctor's or other clinical personnel's speaking Spanish. Although 89% of the women with lower acculturation scores felt it was important that their doctor speak Spanish, only 49% of those with higher acculturation scores felt this was important ($P = .001$). Similar proportions of more and less acculturated women felt it was important that someone in the clinic speak Spanish (89% vs 51%, respectively; $P < .001$). Surprisingly, in this subset of 726 women, having a primary care doctor who spoke Spanish was not significantly associated with higher odds of receipt of ever or recent clinical breast examinations or mammograms (data not shown).

Discussion

Previous studies on breast cancer screening and acculturation have focused on Mexican Americans in California and the Southwest; this study is unique in its focus on Colombian, Dominican, Puerto Rican, and Ecuadorian Hispanic women in New York City. For these women, greater acculturation was significantly associated with higher rates of screening by clinical breast examination and mammogram. This relationship held after adjustment for socioeconomic status, health status, demographic and health system characteristics, and cancer attitudes and beliefs. Consistent with the findings of previous studies, having insurance remained a major predictor of screening use.[16]

Previous studies on breast cancer screening and acculturation have had conflicting results. Some found no statistically significant effect of acculturation on screening utilization,[17–19,22,53] while others did find an effect.[20–21] The studies that found no significant effect all[17–19,22] used a broad measure of acculturation that included not only language use but also social patterns, family values, or ethnic identification. One of the studies that found a significant association between acculturation and screening used a measure that included language, ethnic identification, and birthplace,[20] and the other used only language chosen for the interview.[21]

Placing our results in the context of these previous conflicting findings is compli-

was 62.3% (includes all calls made to identify homes of persons of the ethnic and age groups of interest). Among women who qualified on the basis of age and ethnicity, the rate of refusal to complete the survey was 2.1%.

Table 1 presents the characteristics of the specific Hispanic subgroups. Dominicans tended to be younger and to have lower incomes than members of the other groups. A higher percentage of Puerto Ricans than of the others came to the mainland United States by age 16 years. Puerto Ricans were also more likely than the others to use English for the interview and to have some form of health insurance.

Table 2 presents selected characteristics of women with lower and higher acculturation scores. These characteristics were highly correlated with acculturation (proportion of life spent in the United States, age at immigration) or were significant predictors of screening use in the final multivariate mod-

els (age, education, insurance status, income, type of site of care/usual source of care).

Having higher acculturation, having a usual source of care, having higher income, having health insurance, immigrating to the United States before the age of 16 years, spending a greater proportion of one's life in the United States, and use of English for the interview were each statistically significantly associated in univariate analyses with greater receipt of ever and recent clinical breast examination and mammography (Table 3).

The final multivariate logistic regression models (Table 4) showed that when other covariates were controlled for, women who were more highly acculturated were significantly more likely than less acculturated women to have obtained a clinical breast examination, both ever and recently ($P \le .01$), and to have ever ($P \le .01$) and recently ($P \le .05$) received a mammogram.

. TABLE 3—Continued

	Clinical Breast Examination		Mammography	
	Ever (n = 888)	Recent[a] (n = 882)	Ever (n = 542)	Recent[a] (n = 524)
Health/health system characteristics				
Health status				
Excellent–very good	87.8	70.5	69.4	62.9
Good	86.9	70.8	74.8	66.7
Fair–poor	83.3	62.0*	71.0	58.6
Usual source of care				
Yes	88.7	71.5	75.4	65.8
No	73.6**	50.7**	48.7**	39.5**
Usual site of care				
Private doctor's office	89.5	69.8	71.7	62.9
Emergency room	87.7	72.8	71.1	59.1
Hospital outpatient department	89.6	75.0	88.6	80.5
Public health clinic	87.9	69.7	77.8	62.8
HMO/large health center	88.8	75.0	80.0*	69.5*
Acculturation				
Language preferred for interview				
English	95.8	86.1	81.0	75.9
Spanish	84.0**	64.0**	70.4	60.4*
Age at immigration, y				
≤16	93.1	80.5	83.3	74.3
>16	84.3**	64.5**	69.8*	60.1*
Proportion of life spent in mainland US, %				
≤25	76.4	59.0	60.0	51.9
26–50	87.5	69.1	72.7	61.9
51–75	90.6	67.4	76.3	67.7
>75	98.1	84.6	87.1	80.6
Born in mainland US	95.0**	87.3**	81.2**	71.4*
Acculturation[d]				
Higher	94.5	80.8	79.4	73.4
Lower	82.2**	62.0**	68.9*	58.3**
Cancer attitudes and beliefs				
Cancer anxiety scale				
High	84.6	66.0	70.6	61.1
Low	88.4	70.8	73.1	63.6
Cancer hopelessness scale				
High	84.3	64.3	70.1	69.2
Low	91.8**	78.9**	76.9	57.7**
Concern about cancer				
High	87.5	72.9	71.9	64.8
Low	85.3	64.4**	71.4	60.0
Perceived risk of cancer				
High	86.3	70.3	71.4	62.2
Low	86.2	65.7	71.8	61.9

[a]"Recent" was defined according to 1992 American Cancer Society guidelines, as follows: for clinical breast examination, every year for women older than 40 years and every 3 years or less for women aged 20 through 40 years; for mammography, every 2 years or less for women aged 45 years and older. (Hence, total n's do not add up to 908.)
[b]Not applicable.
[c]Income was missing for women who refused to answer the question or answered "Don't know."
[d]Mean acculturation scores (see text) were as follows: for clinical breast examination, ever vs never = 2.2 vs 1.7*, recent vs not recent = 2.3 vs 1.8*; for mammography, ever vs never = 2.0 vs 1.7*, recent vs not recent = 2.1 vs 1.8*.
*P ≤ .05 for the group (cell); **P ≤ .01 for the group (cell).

turation scales and because it is valid.[58,59] We chose to focus on the linguistic aspects of acculturation because of their relevance to interventions targeting the delivery of health care.

Measures of acculturation that focus on language use have another advantage over broader measures of acculturation: one can establish that language use is associated with the screening behavior. With mixed acculturation measures, components unrelated to the behavior of interest could lower the association between language use and health behavior, perhaps explaining the inconsistency of previous findings in studies of acculturation and health practices of Hispanic adults.[23,24,60]

The second area of controversy is the conceptual framework within which acculturation operates. Limited proficiency in English is associated with socioeconomic factors known to be related to decreased use of health care services.[21,61] If these factors are not controlled for, acculturation may simply act as a proxy for socioeconomic status.[54] Our inclusion of socioeconomic indicators (income, education, work status) in the multivariate models reduces this risk.

Also complicating the conceptual framework is the issue of how language influences health care use. Some see language as a communication barrier between health care provider and patient,[62] while others emphasize the effect on screening practices of language as an access factor.[20] Viewing language acquisition as merely an "access factor" may be an oversimplification. Language influences perceptions, cognitive structure, and self-expression,[63–66] which may affect how Hispanic women interact with providers. Thus, it is likely that language operates on both levels and that some combination of its effects contributes to the likelihood that a woman will obtain recommended screening.

As an example of language's complex role, we found that among the subset of women who chose to be interviewed in Spanish and who were the least acculturated, having someone in the clinic who spoke Spanish was not predictive of screening use. One implication of this finding is that simply introducing translators or Spanish speakers into the clinic, without addressing patients' level of acculturation, may not be sufficient to change behavior. It might be necessary, for example, to involve trained lay health workers from cultural backgrounds similar to those of the target population.[67]

Further community- and practice-based research is needed to evaluate the effectiveness of tailoring cancer screening messages to the acculturation level of the women being served. Further study would also help to clar-

cated by the controversy over deciding how best to measure acculturation and determining the conceptual framework within which acculturation operates. With respect to the first area, some criticize the use of language preference alone as an inadequate measure of acculturation; they contend that the extent to which a person has adopted core values of the host culture should be included.[54] Others argue that language preference is the best measure of cultural integration.[55–57] Many now view language as a reliable shorthand measure of acculturation, because it accounts for the greatest portion of variance of accul-

TABLE 4—Acculturation and Adjusted Odds[a] of Breast Cancer Screening in a Sample of Hispanic Women: New York City, 1992

	Odds Ratio (95% Confidence Interval)			
	Clinical Breast Examination		Mammography	
	Ever	Recent[b]	Ever	Recent[b]
Acculturation[c]	1.82** (1.30, 2.60)	1.35** (1.07, 1.71)	1.59** (1.17, 2.17)	1.34* (1.01, 1.79)
Usual site of care				
Private doctor's office	1.25 (0.60, 2.49)	0.84 (0.48, 1.44)	1.11 (0.54, 2.21)	1.13 (0.57, 2.21)
Hospital outpatient department	1.53 (0.66, 3.54)	1.24 (0.65, 2.35)	4.00** (1.58, 10.7)	3.40** (1.48, 8.02)
Public health clinic	1.55 (0.59, 4.28)	0.97 (0.47, 2.04)	1.82 (0.66, 5.28)	1.33 (0.52, 3.47)
HMO	1.47 (0.59, 3.79)	1.30 (0.64, 2.66)	2.02 (0.82, 5.15)	1.69 (0.73, 3.99)
Emergency room	1	1	1	1
No usual site	0.56 (0.27, 1.13)	0.43** (0.23, 0.77)	0.56 (0.25, 1.21)	0.56 (0.26, 1.22)
Education, y				
<12	1	1	1	1
12–15	1.24 (0.76, 2.04)	1.39 (0.96, 2.02)	1.12 (0.69, 1.83)	1.11 (0.70, 1.79)
≥16	1.86 (0.82, 4.71)	1.90* (1.05, 3.59)	1.25 (0.55, 3.10)	0.89 (0.41, 1.98)
Age, y				
20–44	1	1	NA	NA
45–54	1.48 (0.85, 2.62)	0.68 (0.33, 1.32)	1	1
55–64	3.20** (1.66, 6.35)	1.25 (0.61, 2.49)	1.71* (1.06, 2.80)	1.45 (0.81, 2.59)
≥65	1.16 (0.60, 2.25)	0.66 (0.31, 1.34)	1.17 (0.66, 2.07)	1.03 (0.54, 1.95)
Insurance				
Private	1.62 (0.92, 2.86)	2.10** (1.36, 3.24)	1.75* (1.00, 3.07)	1.49 (0.87, 2.57)
Public only	2.55** (1.47, 4.49)	2.26** (1.47, 3.51)	2.47** (1.38, 4.47)	1.74* (1.01, 3.03)
Uninsured	1	1	1	1
Income, $				
<20 000	0.78 (0.41, 1.45)	0.70 (0.43, 1.10)	0.77 (0.40, 1.47)	0.56 (0.30, 1.04)
≥20 000	1	1	1	1
Missing[d]	0.90 (0.44, 1.82)	0.79 (0.47, 1.32)	1.01 (0.51, 2.00)	0.49* (0.25, 0.94)

Note. Only statistically significant variables from the final model are shown. 1 = reference category; NA = not applicable.
[a]All odds ratios are adjusted for acculturation, type of site of care/usual source of care, education, age, ethnicity, insurance status, marital status, health status, cancer anxiety score, cancer hopelessness score, cancer concern score, and income.
[b]"Recent" was defined according to 1992 American Cancer Society guidelines as follows: for clinical breast examination, every year for women older than 40 years and every 3 years or less for women aged 20 through 40 years; for mammography, every 2 years or less for women aged 45 and older (40–44-year-olds excluded because of quota sample structure).
[c]Acculturation is continuously scaled from 1 (least acculturated) to 5 (most acculturated). Odds ratios for this variable indicate increase in odds of screening per unit increase in the acculturation scale.
*$P \leq .05$; **$P \leq .01$.

ify whether having health care providers with a common language or cultural orientation could lead to improved screening rates for Hispanic women.

Several factors should be considered in interpreting our data, including potential selection bias, use of self-report, and a potential lack of generalizability to persons without telephones or living in rural areas. The women who participated in this study may differ systematically from the nonparticipants; for example, participants may be more likely to have had screening. We do not have data on the nonparticipants. However, the refusal rate among those known to be eligible for the study was low (2.1%).

Use of screening services in this study was determined by self-report. Since the women received care from a variety of settings in New York City, validation of self-reports through medical record review was not practical. Several studies have established that self-reporting usually overestimates the preva-

lence of screening.[66–71] Characteristics that might influence the validity of self-reports, such as acculturation, education and socioeconomic status, have been controlled for in analyses assessing the sample as a whole.

The rates of receipt of clinical breast examination and mammography in our 1992 study seem high relative to commonly cited national rates, most of which are based on data from 1987 and earlier. However, our screening rates are consistent with those from more recent local studies[35] and with Behavioral Risk Factor Surveillance System data from the same period. For instance, a Centers for Disease Control and Prevention study of these data for 39 states[72] found that age-adjusted proportions of women aged 40 years and older who received a mammogram in the preceding 2 years ranged from 43.8% to 65.2% in 1989 and from 63% to 79.7% in 1995.

While the vast majority of Hispanic residents of New York State resided in New York City at the time of the survey,[27] our data may

not be generalizable to Hispanic women living in, or migrating to, rural settings. In 1992, 79% of Hispanic households in New York City had telephones.[73] Personal interviews, the alternative to telephone interviews, are difficult to achieve in the economically depressed areas of New York City where many of the target populations live, because of residents' concern for security. Furthermore, in-person screening for quota samples is extremely inefficient. Despite this limitation, the quota sample is broadly representative of the ethnic groups living in the targeted areas.

An upward trend in screening use among Hispanic women, compared with older data, is reflected in our results and those of other recent studies.[16,68,74] However, recent mammography use is still reported by a higher proportion of Anglo Americans (79%)[16] than either Mexican Americans (61%)[16] or our sample of Hispanic women (52%). Nationally, the same is true of recent clinical breast examination (66% [Anglos] vs 59% [Hispan-
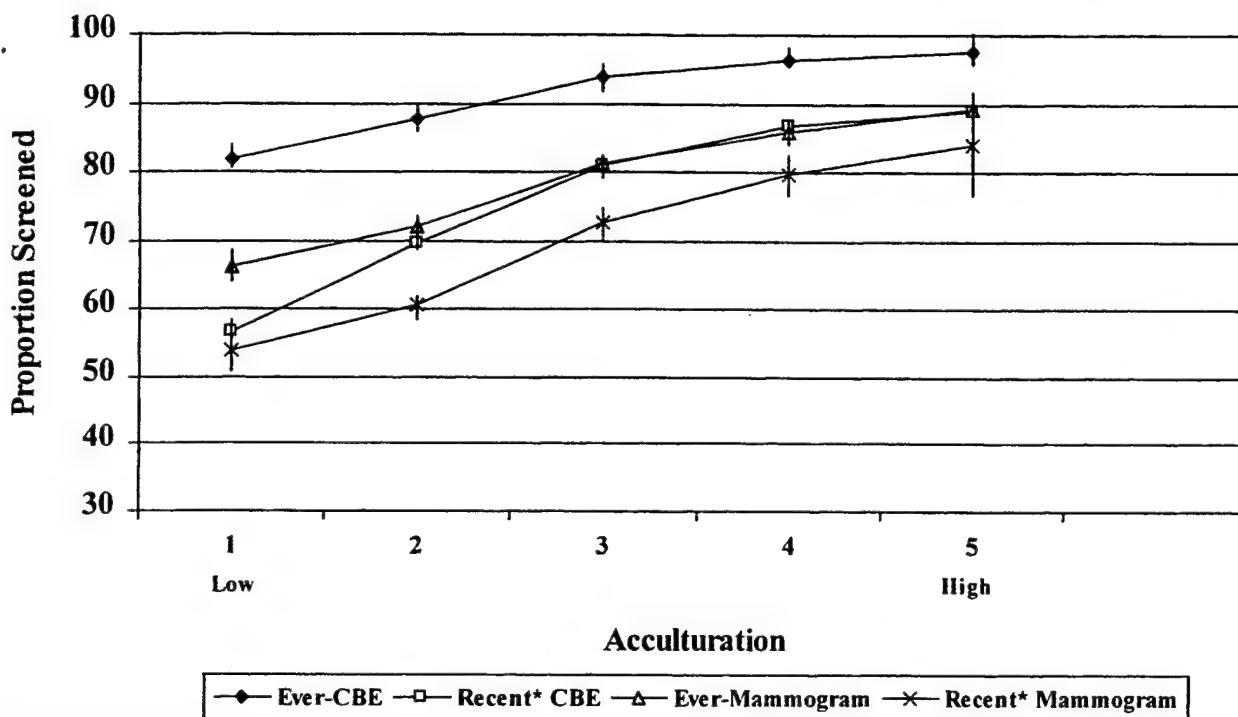
Notes. Vertical line indicates the 95% confidence interval for that adjusted proportion.

"Recent" was defined according to 1992 American Cancer Society guidelines as follows: for clinical breast examination, every year for women older than 40 years and every 3 years or less for women aged 20 through 40 years; for mammogram, every 2 years or less for women aged 45 and older.

Adjusted proportions of women screened are calculated from the logit function based on the multivariate logistic regression models (see Table 3), which adjust for acculturation; type of site/usual site of care; education; age; ethnicity; insurance status; marital status; health status; cancer anxiety, hopelessness, and concern scales; and income.

FIGURE 1—Adjusted proportions (with 95% confidence intervals) of Hispanic women receiving breast cancer screening, level of acculturation.

ics]).[74] In our sample, recent clinical breast examination rates were slightly higher (68%), especially among the more acculturated.

The Department of Health and Human Services already recognizes the importance of language and culture in health promotion programs serving minority populations and has established a year 2000 goal to "increase to at least 50% the proportion of counties that have established culturally and linguistically appropriate community health promotion programs for racial and ethnic minority populations."[9] Our finding of a strong association between a woman's level of acculturation and whether or not she receives recommended screening reinforces the importance of acculturation in the delivery of breast cancer screening programs to women in these Hispanic subgroups. Although the more acculturated women in this study had screening rates near or even exceeding those set as year 2000 goals—defined as 80% of Hispanic women aged 40 and over have ever received and 60% of Hispanic women aged 50 and over have recently received clinical breast examination and mammography—less acculturated women still have a long way to go if they are to achieve those objectives. The fact that recency of immigration was associated with screening and was strongly collinear with acculturation suggests that targeting programs to areas with a high proportion of recent immigrants may be a useful way to reach less acculturated Hispanic women. □

Contributors

Ann O'Malley developed the research question, performed all data analyses, and wrote the manuscript for this paper. Jon Kerner and Jeanne Mandelblatt were both principal investigators on the National Cancer Institute study responsible for the collection of the dataset and contributed to writing the manuscript. Ayah Johnson provided statistical guidance for the project.

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Inreach and Outreach Interventions to Improve Mammography Use

K. Robin Yabroff, Ph.D., M.B.A. [1]
Ann O'Malley, M.D., M.P.H. [1]
Patricia Mangan [2]
Jeanne Mandelblatt, M.D., M.P.H. [3]

[1]   Research Assistant Professor, Cancer Control Program, Lombardi Cancer Center
and Department of Oncology, Georgetown University Medical Center,
Washington, DC
[2]   Research Assistant, Cancer Control Program, Lombardi Cancer Center and
Department of Oncology, Georgetown University Medical Center, Washington, DC
[3]   Associate Professor and Director, Cancer Control Program, Lombardi Cancer
Center and Department of Oncology, Georgetown University Medical Center,
Washington, DC

Please address correspondence to:
Robin Yabroff, Ph.D., M.B.A.
Research Assistant Professor
Lombardi Cancer Center
Georgetown University Medical Center
2233 Wisconsin Avenue NW, suite 440
Washington, DC 20007
Telephone: 202 687-7036
Fax: 202 687-0305
E-mail: yabroffr@gunet.georgetown.edu

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Inreach and Outreach Interventions to Improve Mammography Use

ABSTRACT

Background: Regular mammography use has been shown to reduce breast cancer mortality, yet some women do not receive regular mammograms. Many patient-targeted interventions exist to increase mammography use, but it is unclear whether these interventions are equally effective when performed outside of the medical setting (outreach) versus within the medical setting (inreach).

Methods: We performed a meta-analysis of controlled interventions targeted to patients performed in the United States and published between 1980 and February 2001. Interventions were classified by the setting--inreach or outreach, and the mechanism of action--behavioral, cognitive, sociologic or a combination of strategies. Interventions were also grouped by the type of control group (active or usual care), number of strategies, and mode of delivery. Summary estimates were calculated with DerSimonian and Laird random effects models for each group of interventions.

Results: We included 62 studies with 90 separate interventions. Inreach and outreach interventions were equally effective in increasing mammography use. Compared to active controls, behavioral interventions with multiple strategies increased mammography use by 14.0% (95% CI: 8.7,19.2) in an inreach setting and 18.7% (95% CI: 4.9, 32.4) in an outreach setting. In both inreach and outreach settings, theory-based educational strategies delivered interactively increased mammography use by 10.7% (95% CI: 6.8, 14.7) and 19.9% (95% CI: 10.6,29.1), respectively. Interventions that combined behavioral and theory based educational strategies with usual care controls led to increased mammography use of 14.0% (95% CI: 7.9, 20.2) in inreach settings and 27.3% (95% CI: 14.7, 40.0) in outreach settings. Finally, sociologic interventions increased mammography use by 10.7% (95% CI: 3.4,18.0) and 9.1% (95% CI: 1.7, 13.3) in inreach and outreach settings, respectively.

Conclusions: Within intervention categories based on mechanism of action, mode of delivery, and type of control group, inreach and outreach interventions to increase

mammography use are similarly effective. Effective outreach interventions can be used to target women and communities with low use of medical care and can potentially reach large numbers of women. *in an effort to reduce br. ca disparities.* Inreach strategies can enhance on-going screening use. Ultimate decisions about intervention strategies will depend on characteristics of the target population, practical implementation considerations, and relative cost-effectiveness.

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Introduction

Regular mammography use reduces breast cancer mortality by approximately 30% (1-6). However, historically, utilization has been sub-optimal in underserved populations (7-15) leading to breast cancer control efforts to increase rates of mammography use (16-18). These efforts have been largely successful with dramatic increases in the rates of recent mammography use over the past two decades (7). Yet approximately 15% of women have never had a mammogram (7) and many more do not receive regular mammograms (19-21). These women are more likely to be older (7), minority (7;20), of low socioeconomic status (7;20;21), uninsured or underinsured (19;22) and in many cases, without a usual source of care (23-25).

One of the most important predictors of mammography use is physician recommendation (23;24;26), but women outside of the medical system or without a usual source of care may not be getting this message. As a result, many community-based outreach interventions have been developed to increase mammography use (16). Previous meta-analyses have reported that most interventions are effective in increasing mammography use, but that the magnitude varies by the type of intervention (27-29). It is unknown, however, whether or not outreach interventions are as effective as similar interventions performed within the medical setting (inreach). In this study, we performed a meta-analysis to compare the effectiveness of outreach and inreach intervention strategies for increasing mammography use.

Materials and Methods

Study selection

We used the Grateful Med search mechanism for MEDLINE to identify English language articles on interventions to increase mammography use published between 1980 and February 2001. The search strategy used the subject terms "health behavior", "patient

compliance", "patient acceptance of health care" "attitude to health", "health education" or "health promotion" (N= 123,195) with the terms "mammogram" or "mammography" (N=2,496) in the title.

This combination yielded 441 studies. Study abstracts were reviewed for evidence of random or concurrent assignment of subjects to an intervention or control group, prospective follow-up, and mammography use as an outcome. Only interventions targeted to patients were included. Pre/post designs without control groups were excluded because secular trends to increased mammography use in the past two decades (7;8) would have likely impacted results. Published abstracts were also excluded because they were assumed to be too brief to contain sufficient information to classify interventions. Studies performed outside the United States were excluded because differences across systems of care might limit the generalizability of outcomes to the United States.

From the review of abstracts from the literature search, 67 studies were potentially eligible for inclusion (22;30-94); 24 were subsequently eliminated because they lacked concurrent or randomly assigned control groups (60;62;81;84;89), the intervention was targeted to both patients and physicians (35;44;45;56;76;80;82;94), performed outside of the United States (42;55;88;90;93), or the outcome was not receipt of mammography (64;95). Interventions to increase annual screening (37;61;63;86) were also excluded. This left 43 studies identified from the search. Reference lists of the studies identified from the literature search and published reviews or meta-analyses of interventions (17;27-29;96-99) were reviewed, and a hand-search of the journals *Preventive Medicine*, *American Journal of Preventive Medicine*, and *Cancer Epidemiology, Biomarkers and Prevention* was conducted for 2000- February 2001 to identify other eligible studies. 19 additional studies were identified in this manner (100-127), and a total of 62 studies are included in this paper.

Data abstraction

Data were abstracted from studies using a standardized abstraction format to describe the intervention setting, type of intervention, means of determining mammography outcome (e.g., self-report, chart), characteristics of the patient population, and intervention effectiveness. Studies were classified as inreach or outreach based on how the patient population was recruited—either within the medical setting (inreach) or outside of the medical setting (outreach). Each intervention within a study was abstracted separately. Within studies, interventions were classified as behavioral, cognitive, sociologic or a combination of these using a classification scheme (128) that has also been used in other meta-analyses of interventions to increase preventive behaviors (28;129;130).

Behavioral interventions change stimuli associated with mammography use (e.g., reminders), and were further classified by the number of separate strategies (e.g., multiple reminder vs. single reminder). Cognitive interventions provide new information and educate women about mammography and clarify any existing misperceptions. Cognitive interventions were categorized further to reflect whether or not the educational strategy was individually tailored or used theory-based messages to help a woman overcome barriers to utilize mammography (e.g., health belief model) or provided generic educational materials, and whether or not the intervention was delivered interactively (e.g., by telephone or in-person) or statically by letter or pamphlet. Sociological interventions utilize social norms or peers to increase mammography use. Interventions that used multiple strategies (e.g., behavioral and cognitive) were classified as such.

Interventions were classified further based on the type of control group. Studies with active controls included a lower level intervention to increase mammography use (e.g., postcard reminder) as the control group. Studies in which the control group did not receive any

specific strategies to increase mammography use were classified as having usual care controls.

Data Analysis

Effect sizes and 95% confidence intervals (CI) were calculated for each intervention. Authors were contacted in cases where data presented in the underlying paper were insufficient to calculate effect sizes and 95% CIs. For randomized studies, intervention effectiveness was calculated as the difference in mammography use between the intervention and control group at the end of the study. Variance was calculated for binomial proportions for intervention and control groups.

For concurrently controlled studies, the effect size was calculated as the difference between the rates post- and pre-intervention for the intervention group and the control group ($[P_{screened\ post-intervention} - P_{screened\ pre-intervention}] - [P_{screened\ post-control} - P_{screened\ post-intervention}]$. Variance was calculated for the binomial proportions for intervention and control groups both prior to, and after, the intervention.

Within each group of intervention (e.g., theory based cognitive outreach interventions delivered interactively and compared to active controls), the effect size and 95% confidence interval for each intervention was graphed and graphs were inspected visually for signs of heterogeneity. Data from groups of interventions were combined with the DerSimonian and Laird random effects models with the software Meta-Analyst (131). Homogeneity within each group was assessed with the Q-statistic and compared to a X^2 distribution. Sensitivity analyses were performed by sequentially eliminating a single study and recalculating the summary effect size, confidence interval, and Q-statistic.

Results

Of the 62 studies included in the meta-analysis, there were 90 separate interventions (Table 1) (30-34;36-39;43;46-50;52;53;57-59;61;65;66;68;70-74;77;78;83;85;87;91;101;102;104;105;107;109-120;122-126;132-134). A little more than half of the studies utilized inreach strategies and the most common type of intervention was a theory-based cognitive strategy. 50 studies were randomized controlled trials and 12 were concurrently controlled studies. The most common outcome measure was patient self-report of mammography use. The patient population was predominantly white, aged 50 and above, with health insurance, and prior mammography use.

Behavioral interventions

Of the 24 patient-targeted behavioral interventions identified (36;49;49;57;58;66;70;77;78;85;91;104;115;116;116;133;135); only three utilized outreach to identify patient populations (49;77;116) (Table 2). Two inreach strategies used financial incentives or vouchers to increase mammography use, both were effective (59;69). Findings for behavioral interventions compared to usual controls and single behavioral strategies compared to active controls have been reported elsewhere (28). When compared to active controls, multiple inreach behavioral interventions increased mammography use by 14.0% (95% CI: 8.7, 19.2). Similarly, multiple outreach behavioral interventions increased mammography use by 18.7% (95% CI: 4.9, 32.4). The Q-statistic for these two estimates was small, indicating homogeneity of effect among the interventions.

The Q-statistic for most of the other groupings of interventions also indicated that these interventions were fairly homogeneous. The exceptions were behavioral interventions with usual care controls and single strategy behavioral interventions compared to active controls. Although the relatively high Q-statistics (19.3 and 17.3, respectively) indicated heterogeneity, sensitivity analysis did not identify a single study associated with the

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heterogeneity. In all cases, sensitivity analysis with sequential removal of each intervention did little to change the interpretation of these estimates.

Cognitive interventions

Of the 35 interventions that used cognitive strategies (31;32;34;36;38;46;47;47;48;50;58;65;68;71;71-74;78;78;83;101;110;114;118-120;122;123;132;134), most were delivered within the medical setting (inreach) (Table 2). The majority of inreach and outreach interventions used theory based education or individually tailored education to increase mammography use (31;32;34;36;38;46-48;58;65;68;71-74;78;83;101;110;114;120;122;123;132;134) .

Generic education strategies were largely ineffective in both inreach and outreach settings. Theory based cognitive interventions were further grouped by whether they were delivered interactively, in-person or by telephone, or by letter or videotape, in a more static manner. Compared to active controls, interactive theory based cognitive *inreach* interventions increased mammography use by 10.7% (95% CI: 6.8, 14.7) whereas theory-based cognitive interventions delivered statically had little impact on mammography use (summary estimate: 1.8 (95% CI: -5.3, 8.5). Similarly, interactive theory-based cognitive *outreach* interventions were more effective than static interventions, with increases in mammography use of 19.9% (95% CI: 10.6, 29.1) and 2.7% (95% CI: -1.5, 6.8), respectively.

These groupings led to relatively homogeneous summaries, and sensitivity analyses did not change the interpretation of most of these estimates. The exception was the grouping of theory-based inreach strategies delivered interactively. A single intervention was eliminated from quantitative analyses (120), because it was associated with the heterogeneity. Elimination of this study had little impact on the summary estimate (9.8; (95% CI: 5.8,13.8) with the intervention and 10.7; (95% CI: 6.8,14.7) without the intervention), and reduced

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heterogeneity dramatically. After removal, sensitivity analysis did not impact interpretation of the summary estimate.

Behavioral and Cognitive

12 interventions used both behavioral and cognitive strategies to increase mammography use (Table 2) (36;43;46;49;68;74;77;87;113;118;124;136). The majority of these were outreach interventions. Compared to usual care, the combination of behavioral and theory-based cognitive strategies delivered interactively were effective in increasing mammography use, leading to a 14.0% increase (95% CI: 7.9, 20.2) in an inreach setting and a 27.3% increase (95% CI:14.7, 40.0) in an outreach setting. These groupings of interventions were relatively homogeneous; interpretation of estimates did not change with sensitivity analysis.

Sociologic interventions

Seventeen interventions tested a sociologic strategy to increase mammography use (33;36;39;43;46;49;49;50;52;53;61;77;87;102;103;105-107;109;111;113;118;124-126); the majority used outreach strategies (Table 2). Interventions that used only interactive sociologic strategies led to increased mammography use in both inreach and outreach settings, 10.7% (95% CI: 3.4, 18.0) and 9.1% (95% CI: 1.7, 13.3), respectively. The Q-statistics were relatively small for these groups of interventions and sensitivity analysis did little to change estimates.

Discussion

This study was designed to determine the relative effectiveness of different approaches to increasing mammography use—inreach to women within the medical care setting and outreach to women outside of the medical setting. We found that within categories of interventions defined by mechanism of action, mode of delivery, and type of control group, the effectiveness of inreach and outreach interventions designed to increase mammography

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use was remarkably similar. Most interventions led to increased mammography use, and, as has been reported previously, interventions appear to be more effective when compared to usual care controls than to active controls (28). Additionally, behavioral interventions with multiple strategies are more effective than those with single strategies, and theory-based cognitive interventions are more effective when delivered interactively, by telephone or in person, than when delivered in a more static fashion, in letters, pamphlets, or videotape (28).

These findings have important implications for continued breast cancer control efforts. In the past ten years, the number of women reporting having received a recent mammogram in the United States has increased dramatically (7). Targeted cancer control intervention efforts (16), implementation of quality of care measures for managed care organizations (i.e., HEDIS) (137), and wider availability of low-cost and no-cost mammography through programs such as the National Breast and Cervical Cancer Early Detection program (NBCCEDP) (18) appear to have played an important role in this increase. Despite these efforts, as many as 15% of women have never received a mammogram (7). As these women may be more likely to be without a usual source of care or without health insurance (7), well-designed outreach interventions may be particularly effective in increasing the rate of first time use of mammography.

Regular use of mammography is also reported to be low in many different settings (19;21). Well-designed inreach strategies recruiting these women through screening facilities or primary care visits may improve rates of regular mammography use (86;112). The combination of inreach and outreach strategies may also be effective in increasing regular mammography use. For instance a recent study of inreach and outreach strategies with both patient and provider components including chart reminders, visual prompts in examination rooms, lay health educators and church-based programs with theory-based educational

messages, patient reminders, and mass media was very effective in increasing mammography use (138).

Few outreach studies were targeted exclusively to communities rather than specific individuals (33;43), although several had community components (43;125;126). In cases where promotional activities were targeted to communities, the number of women reached, and who potentially changed their behaviors may be much larger than in studies where only specific women were targeted. Thus, effective community outreach interventions may be particularly cost-effective if large numbers of women are impacted. Additionally, in populations or settings where the majority of women have not had a recent mammogram or ever had a mammogram, the cost of the intervention per participant screened may be lower than in populations where most women have had a recent mammogram. Several studies have reported the costs and cost-effectiveness of specific interventions in increasing mammography use (31;54;66;68;73;77;101;134;139), these estimates will be useful for comparing the overall costs and effects of different intervention approaches in different populations and settings.

Some of the studies included in this meta-analysis also assessed the effectiveness of interventions for increasing the use of cervical cancer screening (103;115;126); these interventions appear to be effective in increasing Pap smear use as well (115;126). Much less work has been performed to increase colon cancer screening (140;141), a leading cause of cancer mortality in both men and women (142). In 1999, rates of recent colon cancer screening (fecal occult blood test) were approximately 20% (143). Adaptation of effective inreach and outreach interventions to other cancer sites with effective screening tests to improve screening initiation and ongoing compliance will be an important component of future cancer control efforts.

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There are some limitations with the meta-analyses reported here, including the reliance on published studies, assessment of multiple interventions from a single study, the combination of multiple measures of mammography utilization (e.g., self-report, chart review), and discrepancies between the unit of randomization and the unit of analysis in published interventions. Studies with negative findings may be less likely to be published and identified by our search strategy. As a result, our summarized estimates might overstate the effectiveness of interventions to increase mammography use.

In several cases, a study included several interventions and single control group (32;33;36;46;66;70;71;78;83;110;120). In order to determine effectiveness of each intervention strategy within a given study, each intervention was compared to the same control group. Thus, women in the control group could have been included in the quantitative analysis more than once. However, when sensitivity analyses were performed, exclusion of a single study did little to alter the interpretation of the estimate. This implies that the impact of counting control subjects more than once is likely to be limited.

Studies included here used different mechanisms to identify mammography use including self-report, chart-audit, electronic claims, and mammography facility records. Data from these different sources are not necessarily equivalent. For example, mammography self-report has been reported to overestimate utilization when compared to charts or claims data (144-147), particularly in low-income populations (146). Similarly, the timing of mammography receipt reported differed across the studies, with some studies reporting mammography use within two months of the intervention (36;69;122) and others reporting mammography use in a periods of two years or more (31;43;111;120;126). However, within a given study, women in the intervention and control arms should be equally likely to overstate utilization or report mammogram use over the same time period, so the relative estimate (intervention-control) is unlikely to be affected.

Several studies randomized clinics, physician practices, churches, public housing units, retirement communities, or more broadly defined communities to intervention and control conditions and then performed analysis on the number of women in each of the communities, rather than the unit of randomization (30;31;49;117). Women living within a specific community or treated at a similar clinic are more likely to have similar behaviors and are not independent (148). If the actual unit of randomization or the correlation among women was accounted for in analysis, the estimate of intervention effectiveness would not be affected, but the confidence interval would likely be wider.

Finally, the definition of inreach as women within a medical system and outreach as women outside of a medical system may lead to some misclassification since even within managed care organizations, some women do not utilize primary care. However, as members of a managed care organization, these women typically receive educational mailings and reminders about screening as part of ongoing practice and they technically have "access" to a health care provider, a major predictor of screening (25).

Conclusion

Inreach and outreach interventions to increase mammography use are similarly effective within category of intervention. Ultimate decisions about intervention strategies will depend on characteristics of the target population, practical implementation considerations, and relative cost-effectiveness.

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Table 1. Intervention Characteristics

	Number of Studies (N = 62)	Percentage	Reference
Type of Intervention			
In-reach	34	54.8	(32;34;36;37;47;50;52;53;57-59;66;69;70;72;73;78;85;91;104;107;110;112;115;117-120;122;124;127;132;133)
Out reach	28	45.2	(30;33;38;39;43;46;48;49;61;65;68;71;74;77;83;87;101-103;105;106;109;111;113;114;116;123;125;126;134)
	Number of Interventions (N = 90)		
Patient-Targeted Intervention Strategy			
Behavioral	24	26.7	(34;36;37;49;57-59;66;69;70;73;77;78;85;91;104;112;115;116;133;135)
Cognitive Generic	8	8.9	(38;47;50;71;78;117-119)
Theory-Based or Tailored	27	30.0	(31;32;34;36;38;46-49;58;65;68;71-74;78;83;101;110;114;120;122;123;127;132;134)
Behavioral and Cognitive	12	13.3	(36;43;46;49;61;68;74;77;87;113;118;124)
Sociologic	9	10.0	(33;50;52;102;103;105-107;109)
Behavioral and Sociologic	1	1.1	(53)
Cognitive and Sociologic	4	4.4	(30;33;49)
Behavioral, Cognitive and Sociologic	5	5.6	(39;49;111;125;126)

Study Design	n	%	References
RCT	50	80.6	(30-34;36-38;46-50;52-53;57-59;65;66;68-74;78;83;85;87;91;101;102;104;107;110;112;113;115-120;122-124;127;132)
Concurrently Controlled Trial	12	19.4	(39;43;61;77;105;109;111;114;125;126;133;134)
Mammography Outcome Measurement			
Self-Report	43	69.4	(30-33;36;38;39;43;46;49;61;65;69;71-74;77;83;87;101-103;105-107;109-111;113;114;116-118;120;122;123;125-127;132;134)
Chart audit	9	14.5	(52;66;69;107;112;117;119;133)
Claims or electronic record	11	17.7	(34;47;50-53;57;70;78;104;115;118)
Mammography facility report	8	12.9	(37;53;58;59;85;91)
Not stated	2	3.2	(48;118)
Patient Age Group			
<40	8	12.9	(43;48;68;71;77;91;113)
40-49	33	53.2	(38;39;43;47;48;50;57;59;61;65;68;71;72;74;83;91;101-107;109;110;113;119;123;125;126;133)
50-59	50	80.6	(30-34;37-39;43;46-48;50;52;52;58;59;61;66;68;70-74;78;83;85;91;102-106;112;113;115;116;118-120;122;123;125-127;132-134)
60+	48	77.4	(30-34;38;39;43;46-50;52;53;61;68-73;85;87;91;102;104-106;109;111-120;122;123;125;127;132-134)
Patient Race			
>20%Black	18	29.0	(30;36;39;49;50;52;53;57;69;102;103;111;112;114;117;120;122;132)
>20% Hispanic	4	6.5	(43;59;105;106)
>20% Asian/Pacific Islander	4	6.5	(109;119;125;126)

>20% White	40	64.5	(30-34;36;38;46-50;52;53;61;65;66;68;71-74;77;83;85;87;91;102;104;107;110;113;114;117;119;120;122;123;132;134)
Patient race not stated	11	17.7	(37;58;70;78;101;115;116;118;127;133)
Percentage with Health Insurance			
<50%	5	8.1	(58;59;91;105;106)
50-74%	3	4.8	(33;85;112)
75+%	28	45.2	(30-32;34;47;49;52;57;66;70;74;77;78;87;104;107;109;113-115;118-120;122;124-126;132)
not stated	26	41.9	(37-39;43-46;48;50;61;65;68;69;71;72;83;101-103;110;111;116;117;123;127;133;134)
Previous mammography use			
0-25%	4	6.5	(78;105;110;112)
25-49%	15	24.2	(43;61;69;70;74;77;87;103;106;107;117;119;126;133)
50-74%	15	24.2	(30;32;33;38;39;52;53;72;77;101;109;111;113;114;125)
75-99%	7	11.3	(31;34;46;57;102;134)
100%	4	6.5	(37;49;132)
Not stated	18	29.0	(47;48;50;58;59;65;66;71;73;83;85;91;104;115;116;120;122;123;127)

Table 2. Effectiveness of Inreach and Outreach Interventions to Increase Mammography Use

	Inreach Interventions			Outreach Interventions		
	Number of Subjects	Intervention Effectiveness	References	Number of Subjects	Intervention Effectiveness	References
Behavioral						
Vouchers	199	45.2 (95% CI: 22.1, 68.2) Q = 4.0	(59;69)		NA	
Usual care controls	1,698	13.2 (95% CI: 4.7, 21.2) Q-statistic =19.3	(57;66;85;13 3)		NA	
Active controls Single intervention	5,181	4.6 (95% CI: -0.3, 9.4) Q-statistic =17.3	(58;70;73;78 ;135)		NA	
Multiple Interventions	3,693	14.0 (95% CI: 8.7, 19.2) Q-statistic = 4.9	(70;91;115)	469	18.7 (95% CI: 4.9, 32.4) Q-statistic = 5.5	(49;77;116)
Cognitive Generic Education	3,280	1.4 (95% CI:-3.4, 6.3) Q-statistic =12.0	(47;50;78;11 7-119)	583	1.8 (95% CI: -2.9, 26.5) Q-statistic = 4.2	(38;71)
Theory-based Education Usual care controls	101	5.7 (95% CI: -12.6,24.0)	(127)	1,979	12.7 (95% CI: 6.6, 18.8) Q-statistic = 7.3	(68;71;101;1 14)
Active controls Static	1,293	1.8 (95% CI: -5.3, 8.5) Q-statistic = 5.2	(32;47;78;11 0)	2,091	2.7 (95% CI: -1.5,6.8) Q-statistic = 1.84	(83;123)
Interactive	5,889	10.7 (95% CI: 6.8, 14.7) Q-statistic = 26.7	(31;32;34;36 ;58;72;73;12 0;122)	850	19.9 (95% CI: 10.6, 29.1) Q-statistic =1.6	(48;65)
Cognitive and Behavioral Generic Education Theory-based Education	178	-10.3 (95% CI: -23.0, 2.4)	(124)		NA	
Usual care controls	719	14.0 (95% CI:7.9, 20.2) Q-statistic =0.50	(36;118)	575	27.3 (95% CI: 14.7, 40.0) Q-statistic = 3.1	(68;87)
Active controls		NA		3,503	2.7 (95% CI: -2.0, 7.4) Q-statistic = 11.7	(43;46;74;77 ;113)

Sociologic	2,115	10.7 (95% CI:3.4, 18.0) Q-statistic = 5.6	(50;52;107)	5,367	9.1 (95% CI: 1.7,13.3) Q-statistic = 9.1	(33;102;103; 106;109)
And behavioral	460	22.0 (95% CI: 14.1, 29.9)	(53)		NA	
And cognitive		NA		7,690	3.2 (95% CI: 1.3, 5.1) Q-statistic = 1.4	(30;33;49)
And behavioral and cognitive		NA		1,222	12.3 (95% CI: 3.1, 21.4) Q-statistic = 10.0	(39;49;111;1 26)

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Appendix 1. Behavioral Interventions to Improve Mammogram Use

			Intervention	Control	Intervention	Control	Effect	95% CI
In-reach Interventions	Vouchers	Kiefe, 1994 (69)	61	78	27 (44.0)	6 (10.0)	33.9	(19.2, 48.6)
		Skaer, 1996 (59)	40	40	30 (87.5)	7 (17.5)	57.5	(39.5, 75.4)
	Usual care control	Landis, 1992 (85)	41	43	6 (14.6)	2 (4.7)	9.9	(-2.7, 22.7)
		Dickey, 1992 (133)	NA	NA	Pre (40.9) Post (57.0)	Pre (37.3) Post (46.0)	7.5	NE
		Mohler, 1995 (66)	38	38	7 (18.0)	4 (11.0)	7.0	(-8.8, 22.8)
		Mohler, 1995 (66)	38	38	11 (29.0)	4 (11.0)	18.0	(0.5, 35.5)
		Mohler, 1995 (66)	37	38	16 (43.0)	4 (11.0)	32.0	(13.2, 50.8)
		Lantz, 1995 (104)	377	322	88 (26.1)	28 (8.7)	17.3	(11.7, 22.9)
		Burack, 1996 (57)	388	381	106 (27.4)	97 (25.4)	2.0	(-4.3, 8.2)
	Active controls, Single Intervention	Turner, 1990 (135)	98	130	18 (18.4)	25 (19.2)	-1	(-11.2, 9.2)
		Ornstein, 1991 (112) *	329	266	56 (21.0)	73 (27.4)	-6.4	(-13.3, 0.5)
		Curry, 1993 (78)	447	440	110 (24.6)	121 (27.5)	-2.9	(-8.7, 2.9)
		Taplin, 1994 (70)	329	329	150 (45.6)	154 (46.8)	-1.2	(-8.8, 6.4)
		Taplin, 1994 (70)	335	329	196 (58.5)	154 (46.8)	11.7	(4.5, 18.9)
		King, 1994 (73)	381	364	159 (41.7)	100 (27.5)	14.2	(7.5, 20.9)
		King, 1994 (73)	198	198	28 (14.1)	23 (11.6)	3.1	(-3.5, 9.8)
		Margolis, 1996 (58)	384	424	306 (79.7)	316 (74.5)	5.2	(-3.5, 14.5)
		Saywell, 1999 (36)	113	110	17 (15.0)	20 (18.2)	-3.2	(-13.0, 6.6)
	Active control, multiple interventions	Wolosin, 1990 (91)	343	344	250 (72.9)	186 (54.1)	18.8	(11.7, 25.9)
		Taplin, 1994 (70)	334	329	206 (61.7)	154 (46.8)	14.9	(7.4, 22.4)
				33				

			1171	1171	310 (26.5)	187 (16.0)	10.5	(7.2, 13.8)
Outreach	Active control, multiple interventions	Somkin, 1997 (115)						
		Mayer, 1993 (77)	32	31	15 (46.9)	6 (19.4)	27.5	(5.3, 49.7)
		King, 1998 (49)	95	122	20 (21.1)	16 (13.1)	8.0	(-2.1, 18.1)
		Shenson, 2001 (116)	97	92	48 (49.5)	22 (23.9)	25.6	(12.3, 38.8)

* Excluded from quantitative analysis

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Appendix 2. Cognitive Interventions to Improve Mammogram Use

			Intervention	Control	Intervention	Control	Effect	95% CI
In-reach interventions		McPhee, 1989 (119)	216	216	104 (48.1)	97 (44.9)	3	(-6.4, 12.4)
	Patient-targeted Generic Education	Currry, 1993 (78)	595	440	161 (27.1)	121 (27.5)	-0.4	(-5.9,5.1)
		Herman, 1995 (117)	159	161	50 (31.4)	29 (18.0)	13.4	(4.1,22.7)
		Davis, 1997 (118)	132	131	12 (9.0)	20 (15.0)	-6.0	(-13.8, 1.8)
		Davis, 1998 (50)	147	147	26 (18.0)	31 (21.0)	-3.0	(-12.1, 6.1)
		Rakowski, 1998 (47)	479	457	280 (58.5)	251 (54.9)	3.6	(-2.7, 9.9)
	Theory based education, usual care control	Lauver, 1999 (127)	46	55	16 (34.8)	16 (29.1)	5.7	(-12.6, 24.0)
	Theory-based Education, active controls. Static delivery	Curry, 1993 (78)	594	440	162 (27.3)	121 (27.5)	-0.2	(-5.7, 5.3)
		Kreuter, 1996 (110)	24	31	13 (54.0)	17 (55.0)	-1.0	(-27.5, 25.5)
		Kreuter, 1996 (110)	33	31	19 (58.0)	17 (55.0)	3.0	(-21.3, 27.3)
		Rakowski, 1998 (47)	461	457	(63.6)	(54.9)	8.7	(2.4, 15.0)
		Rimer, 1999 (120)	128	128	105 (82.0)	110 (85.9)	-3.9	(-12.9, 5.1)
		Lipkus, 2000 (32)	366	362	245 (66.9)	221 (61.0)	5.9	(-1.1, 12.9)
		King, 1994 (73)	202	198	57 (28.0)	23 (12.0)	16.0	(8.3, 23.7)
	Theory based education, active controls, interactive delivery	Skinner, 1994 (72)	217	218	95 (44.0)	68 (31.0)	13	(4.1, 22.0)
		Margolis, 1996 (58)	264	424	212 (80.3)	316 (74.5)	5.8	(-1.0,12.6)
		Saywell, 1999 (36)	108	110	25 (23.1)	20 (18.2)	4.9	(-5.8, 15.6)
		Saywell, 1999 (36)	129	110	44 (34.1)	20 (18.2)	15.9	(5.0, 26.8)
		Rimer, 1999 * (120)	128	128	109 (85.1)	110 (85.9)	-0.8	(-9.4, 7.8)
		Costanza, 2000 (31)	587	481	459 (78.2)	374 (77.8)	0.4	(-4.6, 5.4)
		Lipkus, 2000 (32)	371	362	263 (71.0)	221 (61.0)	10.0	(3.2, 16.8)
		Taplin, 2000 (34)	590	590	294 (49.8)	209 (35.4)	14.4	(8.8, 20.0)
		Champion, 2000 (122)	232	232	70 (30.2)	39 (16.8)	13.4	(5.4, 20.6)
		Champion, 2000 (122)	232	232	77 (33.2)	39 (16.8)	16.4	(8.3, 23.7)

Out-reach interventions	Generic education	Champion, 2000 (122)	232	232	77 (33.2)	39 (16.8)	16.4	(8.3, 23.7)
		Champion, 1994 (71)	75	78	55 (73.0)	48 (62.0)	11	(-3.7, 25.7)
		Schwartz, 1999 (38)	215	215	148 (69.0)	165 (75.0)	-6.0	(-14.5, 2.5)
	Theory based, usual care controls	Champion, 1994 (71)	73	78	64 (87.0)	48 (62.0)	25.0	(11.8, 38.0)
		Champion, 1994 (71)	74	78	53 (72.0)	48 (62.0)	10.0	(-4.0, 24.8)
		Houts, 1990 (101)	370	242	144 (39.0)	73 (30.0)	9.0	(1.4, 16.6)
		Aiken, 1994 (68)	58	85	16 (27.6)	8 (9.4)	18.2	(5.1, 31.3)
		Fox, 2001 (114)	Pre 434 Post 431	Pre 484 Post 491	Pre 244 (56.2) Post 271 (62.9)	Pre 303 (62.6) Post 298 (60.7)	8.6	(-0.3, 17.5)
	Theory based, active controls, static delivery	Rothman, 1993 (83)	90	63	59 (65.9)	33 (55.2)	10.7	(-5.1, 26.4)
		Rothman, 1993 (83)	44	63	25 (57.1)	35 (55.2)	1.9	(-17.2, 21.0)
		Marcus, 1993 (123)	870	961	567 (65.2)	608 (63.3)	1.9	(-2.5, 6.3)
	Theory based, active controls, interactive delivery	Banks, 1995 (65)	67	66	30 (45.3)	22 (33.8)	11.5	(-5.0, 28.0)
		Dalcssandri, 1998 (48)	366	351	100 (27.3)	17 (4.8)	22.5	(17.4, 27.6)

* Excluded from quantitative analysis

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Appendix 3. Cognitive and Behavioral Interventions to Improve Mammography Use

Intervention Category	Author, year	Sample Size		Women Screened		Effect	95% C
		Intervention Number	Control Number	Intervention Number (%)	Control Number (%)		
In-reach interventions Generic education	Clementz, 1990 (124)	102	76	19 (18.6)	22 (28.9)	-10.3	(-23.0, 2.4)
Theory-based education	Davis, 1997 (118)	132	131	37 (28.0)	20 (15.0)	13.0	(3.2, 22.8)
	Saywell, 1999 (36)	118	110	36 (30.5)	20 (18.2)	12.3	(1.3, 23.3)
	Saywell, 1999 (36)	118	110	42 (35.6)	20 (18.2)	17.4	(6.1, 28.7)
Theory-based education, usual care controls	Richardson, 1996 (61)	Pre 172 Post 172	Pre 195 Post 195	Pre NS Post 69 (40.0)	Pre NS Post 58 (29.8)	NA	NA
	Aiken, 1994 (68)	78	85	23 (29.5)	8 (9.4)	20.1	(8.3, 32.0)
	Rimer, 1992 (87)	213	199	96 (45.0)	24 (12.0)	33.0	(24.9, 41.1)
Out-reach interventions Theory-based education, active controls	Mayer, 1993 (77)	384	379	Pre 180 (46.9) Post 238 (62.0)	Pre 200 (52.8) Post 240 (63.0)	4.9	(-4.9, 14.7)
	Bastani, 1994 (74)	313	313	157 (50.0)	175 (56.0)	-6.0	(-13.8, 1.8)
	Bastani, 1999 (113)	382	371	249 (65.2)	214 (57.7)	7.5	(0.6, 14.4)
	Crane, 1998 (46)	319	293	64 (20.1)	61 (20.8)	-1.0	(-7.1, 5.7)
	Crane, 1998 (46)	305	293	65 (21.3)	61 (20.9)	1.0	(-5.0, 7.0)
	Fox, 1999 (43)	Pre 75 Post 101	Pre 56 Post 70	Pre 9 (12.0) Post 27 (27.0)	Pre 13 (23.0) Post 17 (24.0)	14.0	(-4.7, 32.7)

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Appendix 4. Sociologic Interventions

			Intervention	Control	Intervention	Control	Effect	95% CI
In-reach interventions	Sociologic	Weber, 1997 (52)	165	173	(29)	(11)	15.2	(7.2, 23.2)
		Davis, 1998 (50)	147	147	44 (29).	31 (21)	8.0	(-2.0, 17.9)
		Margolis, 1998 (107)	772	711	535 (69.3)	447 (62.9)	6.4	(1.6, 11.2)
	Sociologic and Behavioral	Janz. 1997 (53)	223	237	85 (38.0)	37 (16.0)	22.0	(14.1, 29.9)
Out-reach interventions	Sociologic	Calle, 1994 (102)	289	305	142 (49.0)	104 (34.0)	15	(7.1, 22.7)
		Suarez, 1997 * (105)	Pre 450 Post 450	Pre 473 Post 473	Pre 96 (21.4) Post 171 (38.1)	Pre 114 (24.1) Post 205 (43.3)	-2.5	(-10.8, 5.8)
		Sung, 1997 (103)	80	94	47 (58.7)	45 (47.9)	10.9	(-3.9, 25.7)
		Navarro, 1998 (106)	56	57	32 (56.4)	25 (43.6)	12.8	(-5.5, 31.1)
		Gotay, 2000 (109)	Pre 129 Post 137	Pre 158 Post 167	Pre 97 (75.2) Post 110 (80.3)	Pre 119 (75.3) Post 134 (80.2)	0.2	(-13.2, 13.7)
		Andersen, 2000 (33)	1600	1667	1260 (78.8)	1252 (75.1)	3.7	(0.8, 6.6)
	Sociologic and Cognitive	King, 1998 (49)	109	109	20 (18.3)	14 (12.8)	5.5	(-4.2, 14.2)
		Andersen, 2000 (33)	1632	1667	1259 (77.1)	1252 (75.1)	2.0	(-0.9, 4.8)
		Anderson, 2000 (33)	1693	1667	1332 (78.7)	1252 (75.1)	3.6	(0.8, 6.5)
	Sociologic, Behavioral, and Cognitive	Duan, 2000 (30)	416	397	321 (77.2)	285 (71.8)	5.4	(-0.6, 11.4)
		Bird, 1998 (126)	Pre 174 Post 197	Pre 176 Post 193	Pre 64 (37.0) Post 108 (55.0)	Pre 56 (32.0) Post 54 (28.0)	22.0	(8.3, 35.7)
	Sociologic, Behavioral, and Cognitive	King, 1998 (49)	109	109	16 (15%)	14 (13%)	2.0	(-7.1, 11.1)
		Erwin, 1999 (39)	152	140	Pre 80 (52.4) Post 98(64.4)	Pre 85 (60.4) Post 89(63.3)	9.1	(-6.7, 24.9)
		Skinner, 2000 (111)	Pre 104 Post 163	Pre 136 Post 174	Pre 53 (51.0) Post 109 (67.0)	Pre 73 (54.0) Post 92 (53.0)	17.0	(0.6, 33.4)
		Jenkins, 1999 (125)	NS	NS	Pre (52.6) Post (55.1)	Pre (46.6) Post (45.6)	3.5	NA

* Excluded from quantitative analysis

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Low-Income Women's Priorities for Primary Care

A Qualitative Study

ANN S. O'MALLEY, MD, MPH;

CHRISTOPHER B. FORREST, MD, PHD;

AND

PATRICK G. O'MALLEY, MD, MPH

Washington, DC, and Baltimore and Bethesda, Maryland

BACKGROUND ■ Because of their challenging social and economic environments, low-income women may find particular features of primary care uniquely important. For this qualitative study we explored which features are priorities to women from low-income settings and whether those priorities fit into an established primary care framework.

METHODS ■ We performed a qualitative analysis of 4 focus groups of women aged 40 to 65 years from 4 community health clinics in Washington, DC. Prompted by semistructured open-ended questions, the focus groups discussed their experiences with ambulatory care and the attributes of primary care that they found important. The focus groups were audiotaped, and the tapes were transcribed verbatim and coded independently by 3 readers.

RESULTS ■ The comments were independently organized into 5 content areas of primary care service delivery plus the construct of patient-provider relationship in the following order of frequency: accessibility (37.4%), the physician-patient relationship (37.4%), comprehensive scope of services (11.5%), coordination between providers (6.8%), continuity with a single clinician (3.7%), and accountability (3.2%). Commonly reported specific priorities included a sense of concern and respect from the clinicians and staff toward the patient, a physician who was willing to talk and spend time with them (attributes of the physician-patient relationship), weekend or evening hours, waiting times (attributes of organizational accessibility), location in the inner city and on public transport routes (an attribute of geographic accessibility), availability of coordinated social and clinical services on-site; and, availability of mental health services on-site (attributes of comprehensiveness and of coordination).

CONCLUSIONS ■ All attributes of care that were priorities for low-income women fit into 1 of 6 content areas. Specific features within the content areas of accessibility, physician-patient relationship, and comprehensiveness were particularly important for these women.

KEY WORDS ■ Primary health care; poverty; health priorities; patient satisfaction; women. (*J Fam Pract 2000; 49:141-146*)

The literature examining specific attributes of the structure and process of primary care for lower-income populations that suffer from disproportionately poor health[1] is relatively modest.[2] Most research in primary care has been undertaken in predominantly insured middle-class private settings and in children.[3-8] There may be particular features of primary care that are uniquely important to low-income women given their challenging social and economic environments.

Ideally, primary care provides entry into the system for all new health needs, involves person-focused (not disease-oriented) care over time, includes care for all but very uncommon or unusual conditions, and coordinates services delivered by multiple providers.[9] In accepted conceptual frameworks of primary care, the essential features include: a comprehensive range of services, coordination across providers, continuity with a single provider, an accessible source of care, and accountability.*[9-10]

The purposes of our qualitative study were to determine which particular attributes of primary care were priorities for low-income women and to investigate whether an accepted framework for the conceptualization of primary care[9-10] corresponds to the priorities of low-income women aged 40 years and

*Definitions for these features can be found on the *Journal's* Web site, www.jfampract.com.

TABLE 1

Focus Group Questions

When you think about the place where you go for health care, what kinds of things are most important to you?
What do you think about the care that you receive at (XYZ) clinic?
What are the good things about your care there?
What are the bad things about your care?
Is there anything about your care that could be improved?
What would keep you from coming to (XYZ) clinic if you needed care or had any type of questions about your health?
What would be the characteristics of the ideal clinic, that would make you want to go there for your care?
Where would this clinic be located?

NOTE: A short demographic questionnaire was circulated and read aloud with the women at the end of each focus group.

older. We hypothesized that themes raised by low-income women would fit into an established framework of primary care, but particular attributes of the features of primary care would be especially important to this vulnerable population.

METHODS

Study Design

We recruited focus group participants using posters and flyers circulated at 4 community clinics in Washington, DC. Those clinics were selected because of their location in medically underserved communities in 3 of the poorest wards of Washington, DC, and because they were examples of the range of structure and funding sources. We used in-depth interviews, audiotaped focus groups,[11] and content analysis of the verbatim transcripts[12] to identify attributes of primary care that are important to low-income women. At completion of the fourth focus group, similar themes continued to be raised, indicating saturation of themes. Through an iterative process of listening to audiotapes and reading transcripts, an exhaustive taxonomy was created that identified groups of issues that low-income women identified as important in the receipt of primary care.

Focus-Group Participants

The participants were English- or Spanish-speaking women aged 40 years or older who used the clinic for their current care or who had used the clinic in the past and were able to give informed consent. Since our qualitative study is the first component of a larger study to assess the relationship between priorities for primary care and receipt of cancer screening services for low-income women, we restricted the sampling frame to women aged 40 years and older.

Conduct of Focus Group Sessions

A separate focus group was held for each clinic. All focus groups were conducted in convenient, safe, and neutral community settings, and clinic staff was not present. The sessions lasted approximately 2

hours. A total of 24 women participated in the 4 focus groups: 2 of predominantly African American patients facilitated by an independent experienced African American female moderator and 2 of Spanish-speaking patients, conducted in Spanish by an experienced Latin American age-appropriate female moderator. A series of open-ended questions was asked of participants to elicit feelings about and experiences with primary care. (Table 1).

Development of Taxonomy

Two study team members (an internist and a physician researcher) independently reviewed each transcript in its entirety, identifying distinct topics (themes) and making comments indicating each of these units of text. Repeated or reworded statements of the same idea by the same participant were listed together as one comment.

Each unit of text (a statement that conveyed one idea) from the transcripts was listed by a physician primary care researcher in the order it arose in the transcripts as both a direct quote and as a summary theme on the basis of the comments made by the first 2 study team members. Initially, to avoid imposing any particular framework onto the women's comments, 2 investigators did independent inductive coding,[13-14] in which each unit of text was reviewed in its context from the transcript, categories (labels) were generated, and a list of labels was compiled. When reviewing this exhaustive list, we found that the list of inductive labels (codes) fit fairly well into established conceptual frameworks for primary care. Thus, all units of text from the transcripts were then reclassified independently in duplicate (by a clinical internist and by a physician primary care researcher), using agreed-upon coding rules from the primary care conceptual framework, with the addition of the physician-patient relationship category, which arose as a common theme from the transcripts.

Interrater reliability for the overall coding of distinct units of text into 1 of 6 major primary care content areas was substantial ($\beta = 0.84$ overall). Content

analysis was performed on the comments for all 4 focus groups, including a count of the number of times a theme was mentioned by different respondents and the primary care content area into which the themes fit.

RESULTS

A total of 24 women participated in the discussions: 8 Latinas, 15 African Americans, and 1 white woman. The mean age of the participants was 46.6 years (median = 44.5; one third were aged 50 years and older.) Eight of the participants had an 11th grade education or less; 5 were high-school graduates; and 11 had some college education. Four were married. The majority worked: 8 full time, 8 part time, and the rest were unpaid, retired, or unemployed. Sixteen of these women cared for dependents part or full time. Eighty-two percent of the participants had a household income of less than

$20,000, reflecting our success in recruiting the population we sought. Twenty-two women were uninsured, but most of the African American participants had had Medicaid or private insurance in the past.

The most important conceptual modification arising from the women's comments was the addition of the physician-patient relationship as an important and unique feature encompassing many of the women's priorities. The percentages of focus group participant comments falling into each of the major primary care codes were as follows: an accessible source of care (37.4%), the physician-patient relationship (37.4%), a comprehensive range of services (11.5%), coordination across providers (6.8%), continuity with a single provider (3.7%), and accountability (3.2%). Table 2 gives the frequency distribution of participants' priorities for primary care and some of the more commonly stated priorities.

Within the content area of the physician-patient

TABLE 2

Sample of Low-Income Women's Priorities for Primary Care Identified in Focus Groups

Accessibility   37.4*

- Available to those without insurance/low costs of services   (12)†
- Attentiveness to waiting times to get an appointment and to be seen once at the clinic   (12)
- Weekend or evening hours/convenient appointment times   (10)
- Doctor and staff fluent in Spanish/test results mailed in Spanish (Hispanic participants)   (9)
- Location in inner city or on public transport   (9)

Physician-Patient Relationship   37.4

- Concerned, respectful staff   (29)
- Doctor willing to talk and listen   (10)
- Clinician from the same culture/knowledgable about the immigrant community (Hispanic participants)   (7)

Comprehensiveness   11.5

- Multiple services available on-site: mental health, counseling, dental, preventive   (8)
- Up-to-date facility and equipment   (6)

Coordination   6.8

- Integration of social services (eg, social security, HUD, food stamps)   (5)
- Ease of getting well-coordinated referrals to outside services and to a wide range of hospitals (5)

Continuity   3.7

- Providers that you know from the past   (6)

Accountability   3.2

- Quality of care   (3)
- Reputation in the community   (2)
- Happy with care (satisfaction)   (1)

HUD denotes US Department of Housing and Urban Development.

*Percentage of total comments for which each content area accounted.

†Number of times each specific theme was mentioned by different individuals.

TABLE 3

Sample Comments from the Focus Groups Organized by Primary Care Content Areas

Category	Sample Comments
Comprehensiveness[9-10]	• "It's really surprising, all the things that are going on in that one clinic. In some ways it's better than a private doctor." • "They even have someone to talk to you about depression." • "I went in to get more blood pressure medicine, and instead of just giving me the medicine, the doctor said that I was supposed to have this done, breast exam, Pap smear, shots. The doctor took the time to give me all this stuff."
Coordination[9-10]	• "They [clinic staff] kept calling me to reach me about my mammogram. It really made me feel good to know that there is someone there who really cares." • "I think the clinic should have a doctor and social worker to go through social security, because if you have a disability, you have to go through a whole lot of problems with your disability."
Continuity[9-10]	• "I had a long treatment and then my Medicaid was cut. The relationship between the doctor and the patient is very important. I wanted to see the same doctor." • "I want a doctor who gets to know me."
Accessibility[9-10]	• "The clinic needs to be right here, in my neighborhood, or near a bus or subway." • "I had chosen a private doctor myself, but I could never talk to her. I could never get in contact with her ... so, that's when I ended up coming back [to the clinic]." • "Communication gets lost with translation. It is not the same if you explain directly to the doctor what you feel, as to tell somebody else who will translate to the doctor in their own way."
Physician-Patient Relationship[27]	• "The whole staff makes you feel like a human being and that you are important." • "I think they give really good care, because the first time I came here, they explained to me what was going on." • "I would like for the doctor to talk with me, to tell me what problems I have, and to have an interest in my concerns."
Accountability[10]	• "You want a high level of health care at a totally professional level." • "If it has a good reputation, you go there, and if you still receive that type of treatment that everybody else says that they are getting there, then that makes you want to go back. Like at [Medicaid managed plan X], I've been there more times in the last couple of months, than I'd been with my other [private] doctor."

relationship, themes mentioned most often were communication between physician and patient, having staff who listen, getting personal attention, and most important, a staff that was concerned and respectful. For Latinas, clinicians' knowledge of the Latin community and of the fear and trust issues experienced by recent immigrants toward the medical system and toward other members of the community were mentioned often.

Specific attributes mentioned frequently within

the category of accessibility were a clinic that had evening and weekend hours, was open to all regardless of insurance status, was located in the inner city or was accessible by using public transport, and was attentive to waiting times. Among Latinas, having a doctor fluent in Spanish and from a similar cultural background was an additional priority.

Within the category of comprehensiveness, the most frequently mentioned themes were the availability of multiple services at one site, presence of an intake procedure that recognized one's needs, coordination of medical and social services on-site, and the availability of counseling and treatment for emotional and mental health concerns. Sample quotes from the focus group transcripts, organized within the 6 content areas, are presented in Table 3.

DISCUSSION

Eighty-six percent of participants' comments fit into 1 of 3 content areas: physician-patient relationship, accessibility, and comprehensiveness. The breadth and depth[9] of physician-patient interactions in primary care make its relationship unique. Heavy emphasis on interactions with their primary care physicians (one third of all comments) supports other authors' statements about vulnerable patients placing a special emphasis on this relationship.[15-16] Underinsured people lacking access to alternate providers have a heightened reliance on a physician's competence, skills, and good will.[15] Having a sense that their physician had concern and respect for the patient was the most frequently mentioned priority in the focus groups. When working with low-income minority or immigrant patients, physicians might want to be especially sensitive to their voice, tone, and posture to communicate a sense of respect and concern for patients who may already feel vulnerable. It appears that the category of physician-patient relationship is vital to the conceptual framework of primary care for these low-income women, and it may be a link in the chain without which the other features (continuity, comprehensiveness, coordination, accessibility, accountability) cannot function optimally.

Accessibility was also a clear priority for these women. Twenty-two of the 24 women in this study were uninsured. This may explain why a large percentage of their comments (37.4%) fell into this category. Even though these uninsured women were receiving medical care in community clinics, issues of access (particularly of organizational access) were still foremost in their minds. This may be due to previous obstacles encountered in obtaining care or to deficiencies or strengths perceived in their current systems. Juxtaposed against the reality of increasing underinsurance for even basic access to services, this underscores a serious and worsening problem of unmet health care delivery needs. This emphasis on accessibility demonstrates the need to improve both the financing and organization of the primary care safety net.

The themes most frequently raised with respect to comprehensiveness highlight how the needs of economically vulnerable people may differ from those who are financially secure. For example, previous research shows that poor women have a higher prevalence of mood disorders than the general population,[18] and most would prefer to be treated for these in the primary care setting,[19-21] since they often do not have the choice of going directly to specialty mental health services. This supports the provision of basic mental health care for the more common and treatable mood and anxiety disorders in the primary care setting. Stronger ties between primary care and certain specialty services may be needed to ensure such comprehensiveness.

A comparison of these participants' priorities with those of the general population in the literature yields similarities and differences. Priorities vary with sociodemographic characteristics[22]: younger patients valued coordination of care and technical proficiency most, while older patients ranked continuity of care and comprehensiveness highest.[23] Older patients placed more emphasis on cost issues[15,23] and on attributes of accountability.[17,24-25] Differences have also been shown by health status: Patients with a chronic illness preferred continuity over other features.[23] In the general population, accessibility, coordination, information, communication, education, respect for patients' values and expressed needs, and emotional support are the greatest concerns.[26] Population differences in priorities demonstrate that primary care systems must be tailored to the specific needs and priorities of the populations served.

Comparison of our study's findings with those of the general population raises the issue of what these low-income women were not saying. For example, issues of accountability were infrequently mentioned. This may reflect the participants' greater concerns with having accessible care. Also continuity of care, while accounting for only 3.7% of comments, was tied to other specific attributes considered important by these women. For example, attributes of the physician-patient relationship, such as communication, are directly tied to the presence of an ongoing relationship with a physician over time. Furthermore, given the dependence of economically vulnerable persons on their primary care physician for access to services and the important role this physician has in coordinating their care, continuity seems especially important.[15]

Limitations

Several limitations should be considered in interpreting these findings. We investigated the research questions in this exploratory study by using focus groups and qualitative analysis. Such methods, if

mindful of established standards,[12] can yield well-grounded and detailed data. However, we cannot determine their generalizability. Further work to rank women's priorities for primary care and to tie them to utilization and health outcomes will be pursued in the future through a population-based study. Also, qualitative data are subject to researcher bias. Our use of 3 independent raters and our careful attention to coding using established methods[12] should have minimized this limitation.

CONCLUSIONS

Established frameworks for primary care, with the addition of the category of the physician-patient relationship, have qualitative (content) validity in this sample of low-income women; therefore, these content areas provide a useful language to discuss their health care delivery needs. The physician-patient relationship, accessibility, and comprehensiveness were the categories into which most of the women's specific priorities fell. Health systems that fail to address low-income women's specific needs may not adequately meet their clients' expectations for health care.

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JFP

AA

Department of Health and Human Services
Public Health Service

Grant Application

Follow instructions carefully.

Do not exceed character length restrictions indicated on sample.

LEAVE BLANK-FOR PHS USE ONLY		
Type	Activity	Number
Review Group Formerly		
Council/Board *(Month/Year)*	Date Received	

1. TITLE OF PROJECT *(DO not exceed 56 characters, including spaces and punctuation)*

Reducing Colorectal Cancer in Low-Income African-Americans

2. RESPONSE TO SPECIFIC REQUEST FOR APPLICATIONS OR PROGRAM ANNOUNCEMENT ☐ NO **x** YES (If "Yes" state number and title)

PAR 99-108 NCI : Cancer Prevention, Control and Pop Sciences Career Development Award

3. PRINCIPAL INVESTIGATOR/PROGRAM DIRECTOR   New Investigator ☐ Yes

3a. NAME (Last, first, middle)	3b. DEGREES	3c. SOCIAL SECURITY NO.
O'Malley, Ann S.	MD, MPH	*Provide on Form Page KK*

3d. POSITION TITLE
Assistant Research Professor

3e. MAILING ADDRESS *(Street, city, state, zip code)*
Lombardi Cancer Center

3f. DEPARTMENT, SERVICE, LABORATORY, OR EQUIVALENT)
Lombardi Cancer Center

The Research Building
Georgetown University Medical Center

3g. MAJOR SUBDIVISION
Oncology

3970 Reservoir Road NW
Washington, DC 20007-2197

3h. TELEPHONE AND FAX *(Area code, number and extension)*
TEL: (202) 687-0862
FAX: (202) 687-0305

E-MAIL ADDRESS omalleva@gunet.georgetown.edu

4. HUMAN SUBJECTS	4a. If "Yes", Exemption no. or IRB approval date		4b. Assurance of Compliance M-1255	5. VERTEBRATE ANIMALS	5a. If "Yes" IACUC Approval	5b. Animal welfare assurance no.
☐No X Yes	Pending {	Full IRB or Expedite Review ☐ ☐		xNo or ☐ Yes		
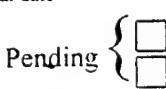
6. DATES OF PROPOSED PERIOD OF SUPPORT (month, day, year—MM/DD/YY)		7. COSTS REQUESTED FOR INITIAL BUDGET PERIOD		8. COSTS REQUESTED FOR PROPOSED PERIOD OF SUPPORT	
From	Through	7a. Direct Costs ($)	7b. Total Costs ($)	8a. Direct Costs ($)	8b. Total Costs ($)
7/01/01	6/30/06	$122,966	$132,803	613,988	663,107

9. APPLICANT ORGANIZATION

Name   Georgetown University
Address   37 & O Streets NW
Washington, DC 20057

10. TYPE OF ORGANIZATION

Public: → ☐ Federal ☐ State ☐ Local
Private: → ☒ Private Nonprofit
For profit: → ☐ General ☐ Small Business

11. ORGANIZATION CODE 01

12. ENTITY IDENTIFICATION NUMBER	Congressional District
1-530196603-A1	DC

13. ADMINISTRATIVE OFFICIAL TO BE NOTIFIED IS AWARD IS MADE

Name   Helen Mourat
Title   Grants and Contracts Officer
Address   Research and Technology Development Services
4000 Reservoir Road NW, Suite 177, Bldg D
Washington, DC 20007-2197
Telephone: (202) 687-1207
Fax: (202) 687-8263
E-mail   mourath@odrge.odr.georgetown.edu

14. OFFICIAL SIGNING FOR APPLICATION ORGANIZATION

Name   William J. Hartman
Title   Director
Address   Research and Technology Development Services
4000 Reservoir Road NW, Suite 177, Bldg D
Washington, DC 20007-2197
Telephone: (202) 687-1390
Fax: (202) 687-8263
E-mail   hartmanj@odrge.odr.georgetown.edu

15. PRINCIPAL INVESTIGATOR/PROGRAM DIRECTOR ASSURANCE:
I certify that the statements herein are true, complete and accurate to the best of my knowledge. I am aware that any false, fictitious, or fraudulent statements or claims may subject me to criminal, civil or administrative penalties. I agree to accept responsibility for the scientific conduct of the project and to provide the required progress report if a grant is awarded as a result of this application.

SIGNATURE OF PI/PD NAMED IN 3A. (*In ink. "Per" signature not acceptable*)

Ann S. O'Malley   DATE 9/25/00

16. APPLICANT ORGANIZATION CERTIFICATION AND ACCEPTANCE:
I certify that the statements herein are true, complete and accurate to the Best of my knowledge, and accept the obligation to comply with Public Health Service terms and conditions if a grant is awarded as a result of this application. I am aware that any false, fictitious, or fraudulent statements or claims may be subject to criminal, civil, or administrative penalties.

SIGNATURE OF PI/PD NAMED IN 14. (*In ink. "Per" signature not acceptable*)

DATE

PHS 398 (Rev. 4/98)   Face Page   AA

DESCRIPTION. State the application's broad, long-term objectives and specific aims, making reference to the health relatedness of the project. Describe concisely the research design and methods for achieving these goals. Avoid summaries of past accomplishments and the use of the first person. This description is meant to serve as a succint and accurate description of the proposed work when separated from the application. If the application is funded, this description as is, will become public information. Therefore, do not include proprietary/confidential information. DO NOT EXCEED THE SPACE PROVIDED.

Low-income, underserved African-Americans have disproportionate colorectal cancer morbidity and mortality. This is partly due to late-stage diagnosis and low receipt of timely screening. Having a usual source of care is a major predictor of screening; however, little is known about specific features of those usual sources of care as they relate to colorectal cancer screening. This proposal assesses specific characteristics of primary care systems associated with receipt of timely screening. Informed by national data and focus groups, a culturally appropriate community clinic-based intervention will be conducted to promote colorectal cancer screening. In striving to help decrease the gap in screening for African-Americans, this project is consistent with NCI's Strategic Plan to Reduce Health Disparities.

The research aims of this proposal are to: *Phase I,* 1) Characterize the population least likely to receive colorectal cancer screening using nationally representative data (Medical Expenditure Panel Survey linked with the National Health Interview Survey—MEPS/NHIS). 2) Examine MEPS/NHIS to identify barriers and facilitators of colorectal screening in low income and minority groups in community clinics. This includes assessment of features of primary care associated with screening. In *Phase II,* the candidate will use these findings to develop and pilot test the feasibility and preliminary effectiveness of a simple low-cost community-clinic based intervention. This intervention will be a randomized controlled trial of a personalized targeted letter to promote colorectal cancer screening. It will be conducted in 360 non-adherent women and men, age 55 and over, from a clinic serving low-income, predominantly African-American persons in Washington, D.C. The findings from phase I (on barriers and facilitators of screening and primary care use) will inform the content of the targeted letter, and the surveys used to assess this intervention. (Yrs 2-5)

This award will provide the time and resources for structured and applied **educational experiences** to ensure the short-term goal of successfully completing this project, and ultimately of becoming an independent investigator. **Major endpoints will be**: 1.) Published papers on features of primary care associated with adherent colorectal screening for low-income adults; and, on the feasibility of the clinic intervention. 2.) Submission of an R01; and, 3.) Disseminating findings to those who impact services for low-income persons. A physician-researcher trained in preventive medicine and public health, the candidate has potential to fulfill the goals of the Cancer Prevention, Control and Population Sciences KO7 Award and to become a fully independent investigator.

PERFORMANCE SITES *(Organization, city, state)*

Lombardi Cancer Center
Georgetown University Medical Center
The Research Building
3970 Reservoir Road NW
Washington, DC 20007-2197

KEY PERSONNEL. See instructions on Page 11. *Use continuation pages as needed* to provide the required information in the format shown

Name	Organization	Role on Project
Ann S. O'Malley, MD, MPH	Lombardi Cancer Center, Georgetown University	P.I.
Jeanne Mandelblatt, MD, MPH	Lombardi Cancer Center, Georgetown University	Mentor
Judith Feder, PhD	School of Public Policy, Georgetown University	Co-Mentor
Christopher B. Forrest, MD, PhD	Johns Hopkins School of Hygiene and Public Health	Consultant
Sally Vernon, PhD	University of Texas, Houston Health Sci Ctr.	Consultant
Yi-Ting Hwang, PhD	Lombardi Cancer Center, Georgetown University	Biostatistician

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Number pages consecutively at the bottom throughout the application. Do not use suffixes such as 3a, 3b.

2

·6. Research Plan

A. SPECIFIC AIMS

Overview: Nationally, lower income African-Americans suffer disproportionately from colorectal cancer morbidity and mortality, compared to the majority population. Annual age-adjusted colorectal cancer mortality rates are higher for Washington, D.C. than for any other state; and, within D.C. rates are highest among African-Americans. Limitations in access to early detection and primary care explain some of this disparity. This proposal will use Andersen and Aday's behavioral model adapted to incorporate vulnerable populations, and the Institute of Medicine's primary care framework. Using this model, the candidate will analyze national data to identify *predisposing, enabling* (including characteristics of primary care) *and need* factors associated with low-income persons' use of colorectal cancer (CRC) screening. These data will then be used to develop and pilot test a community clinic-based intervention, based on the theoretical framework, to increase CRC screening in low-income African-American men and women.

Prior efforts to improve the use of recommended CRC screening through clinic "inreach," (i.e. target populations within a clinical setting) in the U.S. have mostly focused on HMO and insured middle class populations, or on patients already in the office for care. Many prior interventions have been relatively resource intensive and would be difficult to sustain in a resource-constrained environment, such as a public sector or non-profit community clinic. For instance, prior CRC screening inreach efforts targeting lower income persons have included lay health workers, on-site patient-education, or clinician-education with chart reminders. None have focused inreach on clinic enrollees who are not presently in for a visit, who may be lower users of clinic services and hence, among the most at-risk for late-stage diagnosis.

To address this gap, the candidate will conduct a phased research project to identify modifiable enabling and reinforcing factors that affect CRC screening for low-income African-Americans age 55 and over. Fifty-five was chosen as the younger age limit because persons should have had at least one flexible sigmoidoscopy plus FOBT by this age, according to current recommendations. In **Phase I**, the candidate will: 1) Characterize the population least likely to receive CRC screening using nationally representative data (Medical Expenditure Panel Survey linked with the National Health Interview Survey— MEPS/NHIS); and, 2) Examine the MEPS/NHIS database to identify how processes of primary care enable CRC screening utilization (Year 1). Findings from phase I (on barriers and facilitators of screening in primary care) will inform the content of the personalized, targeted letter intervention, (Phase II) as well as the surveys used to assess the process and feasibility of the intervention.

Aim 1. (Phase I): To analyze the Medical Expenditure Panel Survey linked with the National Health Interview Survey, which over-sampled lower income and African-American persons, to test the following hypotheses:

Hypothesis 1a: Specific mutable features of primary care (such as *comprehensiveness of services* and *continuity with a specific clinician*, and *the patient-clinician relationship)* will be more strongly associated with adherence to CRC screening for lower- than for upper-income persons, regardless of insurance status.

Hypothesis 1b: Lower utilization of colorectal cancer screening will be associated with less organizational access to primary care, and more personal barriers to screening in primary care. This effect will be stronger among lower income men than lower income women, controlling for potential confounding variables.

Phase II: Informed by phase I findings, the candidate will design and implement: 1.) Patient focus groups from the community clinic to assure that the intervention is culturally appropriate; and, 2.) A pilot randomized controlled trial of a personalized (to the patient's name) letter, targeted to the patient's stage-of-change, to promote utilization of CRC screening. The RCT will be conducted in a sample of 360 non-adherent women and men, age 55 and over, listed in the database of a non-profit clinic serving low-income, predominantly African-American persons in Washington, D.C. (Years 2-5)

·Aim 2. (Phase II): **To test the feasibility, acceptability, costs and preliminary effectiveness of a simple inreach intervention in community-based clinics.**

Hypothesis 2a. Personalized tailored letter-invitations will be a feasible and acceptable intervention from the perspectives of both staff and patients of the primary care clinic (*process* evaluation).

Hypothesis 2b: Personalized tailored letter-invitations will be *effective* in enabling patients to obtain colorectal cancer screening (FOBT and flexible sigmoidoscopy) within the 1-year follow-up period, controlling for pre-intervention visit frequency, health status and other factors.

If these hypotheses are confirmed, the candidate will expand the intervention to a representative sample of primary care clinics serving low-income persons age 55 and over throughout Washington, DC. Such an RO1 intervention would be broadly transportable to other urban areas to decrease disparities in cancer outcomes as per the goals of NCI's Strategic Plan to Reduce Health Disparities.

B. BACKGROUND, SIGNIFICANCE AND RATIONALE

B1. The Problem—Poor Health Outcomes from Colorectal Cancer: Colorectal cancer (CRC) is the second leading cause of cancer-related death and the third most commonly diagnosed cancer for both men and women in the United States.[8] While colorectal cancer *incidence* decreased 7.4% for the nation during 1973-1995, the incidence among African-Americans increased. Likewise, while the CRC *mortality* rate decreased 20.8% among the general population from 1973-1995, mortality actually increased approximately 20% among African-American males. Annual age-adjusted CRC mortality rates are higher for Washington, D.C. than for any other state, and within D.C. rates are highest among African-American men and women.[9] HP2010 objectives for lowering the CRC death rate set a target improvement of 34% for the total population. This requires even greater improvement among low-income African-American populations since their baseline mortality rates exceed those of the majority population.[10]

Throughout this proposal, screening and mortality rates are presented for blacks/African-Americans vs. the majority population because that is how rates are categorized in national data. Reporting screening rates by race can be misleading since race often reflects social and historical experiences rather than biological categories.[11-14] A large part of the racial disparities in survival from CRC can be attributed to confounding by socioeconomic status, a concept that is difficult to capture and adjust for completely. The intervention phase of this proposal focuses on the lower income population in Washington D.C., which happens to be predominantly African-American. The candidate heeds the words of Dr. Freeman, "Quite apart from skin color or ethnic origin, socioeconomic status is a major variable in racial and cultural differences in cancer mortality."[15] Socioeconomic status will be carefully considered in all analyses and reports of this study.

B2. Evidence that Screening Improves Outcomes: Advanced stage at diagnosis is the primary determinant of poorer CRC survival in low-income blacks, accounting for 50-60% of the excess mortality.[16-17] After adjusting for stage, more aggressive tumor characteristics do not explain the adverse survival.[17] A reduction in CRC deaths can be achieved through detection and removal of precancerous polyps and treatment of CRC in its earliest stages. Having a screen-detected colorectal cancer is strongly associated with diagnosis of early stage disease.[18] Three RCTs indicate that biennial screening with fecal occult blood tests (FOBT) can reduce deaths from CRC by 15 to 21%.[19-22] One trial [19] reported a 33 % reduction in deaths with annual screening in the same age groups, and a simulation model showed a 56 % reduction.[23] The efficacy of sigmoidoscopy has been supported by three case-control studies [24-26] showing 59 to 79 % reductions in CRC deaths from cancers within reach of the sigmoidoscope.[10] Recent studies suggest that colonoscopy is useful to detect precancerous lesions in asymptomatic populations;[27] although, this modality may not be cost-effective.[28]

B3. Current Screening Utilization: Despite the existence of effective screening, utilization rates are low. Among all persons over the age of 50 in the U.S., only 19.8% report having had FOBT in the past year, and 30.4% reported having had a sigmoidoscopy/proctoscopy during the preceding 5 years.[29] In Washington D.C., for all SES groups combined, 36.8% of African-Americans have "ever" used a home blood stool test kit vs. 49.4% of whites.[30] Significantly fewer African-Americans than whites have "ever" had a sigmoidoscopy. In the D.C. screening use among African-Americans varies by income, with low-income individuals being significantly less likely to be screened than their higher income counterparts.[30] Hence, African-American's late-stage diagnosis and increased mortality is likely due in part, to lack of regular screening.[31-32] This effect is especially pronounced in low-income groups.

B4. Conceptual Framework: Many predisposing, enabling and need factors predict screening use.[33] For example, the usual source of care (an enabling factor) plays an important role in facilitating screening adherence[34-35] in addition to other predisposing and enabling factors such as socioeconomic status, insurance, and personal knowledge and beliefs about cancer screening.[36-42] For CRC screening to be maintained at regular intervals over time, this proposal posits that screening needs to be coordinated within the primary care system.[43-45] Once initiated, maintaining screening behaviors is less of a problem.[18,46-50] In addition, understanding the patient's stage-of-change has been very useful for intervention development around other cancer screening behaviors.[51-52] The behavioral model of utilization of screening services,[33] has been adapted to incorporate vulnerable populations,[53] a primary care framework,[43-45] and the stages-of-change[51-52] to examine CRC screening. **This model was chosen because of its relevance to screening in the population of interest. It will be used to analyze factors associated with use of CRC screening for the analyses of MEPS/NHIS data (years 1-2) and for the inreach intervention design and analyses (years 2-5).** We posit that recruitment into primary care through a clinic letter, targeted to the recipient's stage-of-change (assessed at base-line interview), will act in combination with the predisposing, enabling and need characteristics of this population to increase utilization of colorectal cancer screening.

Figure 2. Conceptual Framework : Behavioral Model of Utilization of Screening Services

Population & System Characteristics
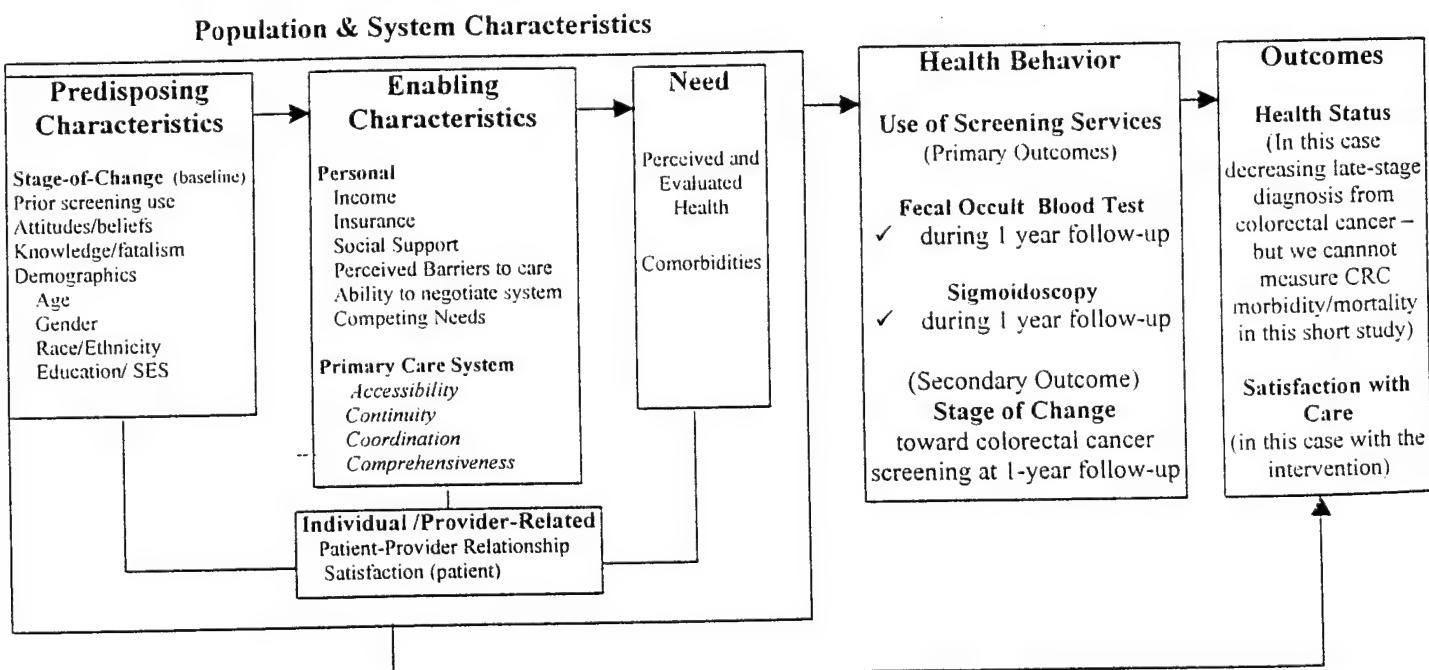
B4.1. Predisposing, Enabling and Need Variables: Efforts to understand and ameliorate the disproportionate CRC mortality among lower income persons are aided by organization of potential determinants of screening utilization into *predisposing, enabling* and *need* factors.[33]

Predisposing Factors - For example, it is known that late-stage diagnosis is more likely in persons living in lower socioeconomic status areas.[38] Other predisposing factors such as gender, race/ethnicity and low-income are associated with differences in rates of FOBT and sigmoidoscopy/colonoscopy.[14, 29, 54]   Even among universally insured populations, racial, gender and socioeconomic disparities exist in the receipt of screening.[34,54-56] Analysis of the role played by these predisposing factors is highly complex, in that most of them mediate and interact with other enabling and need factors to affect screening utilization.[33,53] Patient knowledge, attitudes and beliefs regarding cancer and screening will be incorporated to models for both phases of the proposal.[36-37, 39-42, 57] An additional predisposing factor that will be incorporated into the intervention phase of this proposal is the patient's base-line "stage-of-change" with respect to colorectal cancer screening. The transtheoretical model postulates that the acquisition of healthy behaviors (CRC screening) involves progression through five stages of change: precontemplation, contemplation, preparation, action, and maintenance.[51-52] This factor will be incorporated into the intervention in Phase II (described below). For the phase II intervention, stage-of-change will be measured both at base-line and follow-up to assess for a progression in attitudes toward CRC screening. Hence in the above conceptual framework, stage-of-change is listed as a secondary outcome as well as a predisposing factor.

Enabling Factors- In addition to well-known enabling factors like health insurance [10,45] a major enabler of interest for this proposal is primary care. Limitations in access to early detection and primary care explain some of the differences in CRC morbidity and mortality faced by lower income African-Americans.[58] **In some cases, presence of a usual source of care ameliorates racial disparities in receipt of screening services.**[59] In a national study, presence of a usual source of care, and having had a doctor visit in the past two years, strongly predicted "ever" having had FOBT and flexible sigmoidoscopy.[34] Having a regular source of care is even more strongly associated with receipt of screening for un- and under-insured groups.[2-3] While African-Americans constitute 58% of Washington D.C. residents, they are disproportionately represented among the low income and uninsured groups.[30] There are 81,000 lower-income residents of Washington D.C. who are uninsured.[61] Zacchaeus Free Clinic is one of the private non-profit primary care clinics serving this population. Many of the persons registered with community clinics have presented in the past for an acute illness, but may not come regularly for routine care. **Such low users of primary care, as well as clinic-users nonadherent to CRC screening recommendations, are the primary audience for whom this proposal's inreach efforts will be directed.**

In addition to the link between having a usual source of care and obtaining screening, it is also important to study the specific features of that usual source of care that promote screening utilization. All "usual sources of care" are not the same. For some people, the "usual source" may be an emergency room. Even when the usual source of care is an out-patient clinic or office, there is wide variation in the characteristics of those settings. Little information is available on the specific features (structure and process) of those sources of care as they relate to CRC screening, particularly for *low-income* ($\leq$ 200% of poverty threshold) men and women.[62]

Ideally, one's usual source of care is a 'primary care' site which provides "integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community."[43-45] The integral features of primary care include comprehensiveness of services, coordination, continuity (with a specific site and provider over time), accessibility (organizational, financial and geographic),[45] and the patient-provider relationship.[63-64] Valid and reliable instruments exist to measure the features of primary care.[64] However, most of these have not been extended to low-income settings to identify aspects of primary care which are most relevant to low-income men and women from medically under-served areas.[62, 65] Studies that have begun to assess the associations between specific features of primary care and other cancer screening tests such as breast and cervical cancer screening [3,66] have found positive associations, but have not assessed colorectal cancer screening, nor sampled men. Detailed information on the relationships between specific characteristics of the usual source of care and

.receipt of timely screening is crucial to the design of future inreach interventions.[62]

Need Factors- Health status, as perceived by the patient and by the provider, is the major need factor. It is well known that low-income persons suffer from poorer overall health than persons of higher SES.[10, 67] This complicates their ability to get screened since competing health demands (comorbidities) often occupy the limited time they have with clinicians. Poor health also acts as a barrier to obtaining routine services which may be seen by the patient as less urgent issues not requiring immediate attention.[68] Others have found that patients with more health problems, particularly if related to the disease for which one is screening, may be more likely to obtain screening.[49] Regardless of the direction of this complex relationship, in both phases of this project health status will be considered as an important potential confounder, and/or effect modifier of screening utilization.

B4.2 Clinic-originated letter targeting the Stage-of-Change: Since 94% of African-Americans age 55 and over report a usual source of care[29] this is an ideal setting to target an intervention for CRC screening. If screening is to continue over time with adequate follow-up, it needs to be coordinated by a clinical provider, preferably one with whom the patient is comfortable, trusts, and has a relationship. In an effort to focus on a low-cost clinic-based intervention which has potential for sustainability in a resource-constrained environment, the intervention phase focuses on a clinic originated, personalized (to the patient's name) letter invitation to screening. Tailored letters to clinic enrollees, have several advantages over other types of inreach interventions: With minimal resources and time, they can be targeted to the patient's stage-of-change with respect to screening. They are relatively low cost; and, they may be a culturally preferred form of information transfer for some groups.[69-70]

Numerous studies have been done using tailored print communications and phone counseling to change screening behaviors.[71-73] Letters tailored to the individual's stage-of-change with respect to screening, often assessed via a base-line phone interview, have been used most frequently in breast cancer screening recruitment efforts. If tailored, the letters are more likely to be read and rated highly than if they are not tailored.[72-74] However, most tailored, targeted letters have been assessed in university clinics or in HMOs focusing predominantly on middle class, insured and non-minority patients. Few interventions targeted stage-of-change with respect to CRC screening, especially in low-income African-Americans.

Letters obtained better response rates if they were short,[75] and reassuringly framed.[76] Response rates were similar whether or not letters contained an inside name and address of the recipient, and whether envelopes were handwritten or machine labeled. This suggests that less resource intensive letters were as well received as more costly letters.[75] Response rates varied widely from 22% to 72%.[75, 77-78]

Letters are less costly than phone calls[79] an important issue for any intervention with hopes of sustainability in non-profit clinics. Personal individual-recruitment strategies were more cost-effective than public-wide strategies.[77] An invitation letter without a specified appointment time was more cost-effective than one with an appointment time.[77] Using their own and modeled data, Thompson et al found that in a non-poor, non-minority population, the initial costs of a formal postcard reminder system for hemoccult testing would be offset by savings in long-term care.[80]

Personalized letters may be a preferred means of contact regarding cancer prevention and screening among some groups of patients.[69-70] One early study[80] using a patient reminder postcard in a middle class HMO population to maximize FOBT compliance, found the mailed postcard more effective at increasing screening rates than interactive talks with a clinician. While phone counseling both with and without tailored letters as an adjunct, has been successfully used to target an HMO population of primarily Caucasian middle-class women with few barriers for mammography,[71] it has been less tested in men, and in lower income persons for CRC screening. In a series of focus groups recently conducted among older African-American men,[69] most participants had negative feelings about phone counseling, finding it intrusive, and preferred information in the mailed format because it was less time-consuming, and could be

reviewed on their own schedules. In a smoking intervention among African-American smokers in a community health center, tailored print materials were more effective than tailored phone counseling at increasing cessation.[70]

Mailed personalized letters have been successfully used to recruit populations over age 50 into prevention studies (mostly breast cancer and dietary) in the past.[75,78, 81-84] Most of these studies focused on women in middle-class populations in HMOs, primary care offices and university based clinics.[71, 79, 85-87] Among lower income women, letters have been used for disease prevention interventions.[75, 82, 84] In sum, few of these interventions addressed the needs of low-income women and men with respect to the receipt of a clinic originated personalized invitation, targeted to their stage-of-change for colorectal cancer screening.

B5. Importance of the Topic/ Contributions: The proposed intervention is **unique** in its approach. Prior inreach interventions for CRC screening, especially in lower income and minority populations, have not been explicitly based on a well-established primary care framework.[43-45, 62] More detailed study of the specific structure and process of primary care through nationally representative data (Phase I) which over-sampled for lower income and minority groups, will highlight particular barriers and facilitators of recommended cancer screening for these populations. This will help to focus the proposed, as well as future, interventions to increase screening. In addition, the proposed study is based on a need identified by local primary care providers working directly with the population of interest.

The proposed course of study would **contribute to the cancer control field:** 1.)Detailed nationally representative information on how specific features of primary care systems relate to the use of CRC screening for lower income and minority persons: This will be the first study to examine primary care specific-predictors of screening among a nationally representative sample of low-income African-Americans. 2.) Such information will be valuable in the design of the proposed pilot inreach intervention as well as in other future primary care interventions to enhance screening utilization; 3.)Feasibility and effectiveness study of a clinic-directed, targeted letter intervention to promote screening in an at-risk group. The project's goals address issues of priority for both HP2010 and for NCI's Strategy to Reduce Health Disparities: 1.)colorectal cancer screening, 2.)high-risk minority groups, and 3.)their access to care.

C. PRELIMINARY STUDIES

This section describes the candidate's preliminary work that informs the current proposal. Dr. O'Malley has been working with her proposed mentor for this project Dr. Jeanne Mandelblatt, with her Co-mentor Dr. Feder, and with her consultant Dr. Forrest, first as a research fellow and then as junior faculty. Together they have studied cancer screening practices of low-income persons in the primary care setting.

C1. Continuity of Care and Breast and Cervical Cancer Screening: Initially Drs. O'Malley and Mandelblatt worked together analyzing data on 1420 women collected by Dr. Jon Kerner as part of an NCI-funded study of the general health and cancer prevention needs of blacks and Hispanics living in New York City.[3-5] The PI and her mentors assessed the role of continuity of care, an integral feature of primary care, in the use of breast and cervical cancer screening.[3] Compared with women without a usual source of care, those with a usual site and a regular clinician at that site were 2.63 (p≤.01), 2.83 (p≤.01), and 2.3 (p≤..05) times as likely to have *ever* received a pap smear, CBE, and mammogram respectively; and, were 2.0 (p≤.05) and 2.65 (p≤..01) times as likely to have received a *receipt* pap smear and CBE respectively (manuscript in appendix).[3]

These findings have several implications for the current proposal. First, they highlight the importance of including primary care variables in the proposed screening model. Second, the above findings were most pronounced among the lower income and SES groups. Thus, continuity of care, may be even more important for disadvantaged persons receipt of screening than for the general population.[3] In focus groups

recently completed by Dr. O'Malley with women from community clinics in Washington, D.C., aspects of the patient-provider relationship were extremely important to participants. Having a sense that the provider "respected" and "was concerned about" the patient was repeatedly mentioned by participants. Thus, the patient-provider relationship is an important component of the theoretical framework.[65] Thus, using both the national data and the proposed local intervention, an important question to address will be the role of this integral component of primary care, continuity of care, and the special importance it may have for the patient-provider relationship and for facilitating CRC screening in low-income persons. Third, since these results were for one location, the 1st phase of the proposal will validate these results in a nationally representative sample; and, extend analyses to address additional factors in our model which may affect screening utilization in community-based primary care.

C2. Focus Groups of low-income African-American and Hispanic Women: In prior work, the candidate has successfully recruited participants from lower income clinics and communities in Washington, D.C.: In 1998, the P.I. completed a series of four focus groups of women over age 40 with low incomes, who receive their health care in one of four community health clinics in the District of Columbia. The objective of these focus groups was to elicit the women's: 1) experiences with community-based primary care; 2) feelings about what are the most important features of ambulatory care; and 3) opinions on barriers to and promoters of on-going cervical, colorectal and breast cancer screening in this setting. Twenty-four women participated in the focus groups.[65] Findings from these focus groups will inform the conduction of focus groups of low-income persons in year two of this proposal. The goal of these future focus groups will be to enlist their feedback and revisions on a personalized letter-invitation and their ideas about the facilitators and barriers to recruitment and to receipt of colorectal cancer screening through primary care.

C3. Population-Based Telephone Survey of women in low-income areas of Washington, D.C.: The primary hypothesis pursued by this survey was that *optimal* [43-45] primary care would promote the use of regular breast and cervical cancer screening among lower income women in Washington, D.C. In addition, it was hypothesized that attainment of these women's <u>priorities</u> for primary care[65] would be positively associated with receipt of recommended screening. A total of 1205 women from throughout the poorest census tracts of Washington D.C. completed the bilingual population-based telephone survey. The response rate for completed interviews was 85%. The survey was fielded from Jan-Feb. of 2000. The candidate is in the process of analyzing the data. She has completed initial analyses describing the population recruited, the characteristics of their usual sources of care, and relationships between specific features of primary care and receipt of screening. (Preliminary draft included in the appendix.) This data-set is rich in the depth of primary care and cancer-screening variables it collected. It is also unique in its focus on older, minority, lower-income women from a non-clinical population living within a concentrated geographic area. Analyses done thus far, and lessons learned from the process of focus groups, data collection, and work with the primary care clinics, have relevance to the current proposal. This study was not adequately powered to test for predictors of colorectal cancer screening, and did not sample men. However, information gained from analyses of these data will lay the foundation for analyses to be pursued using the MEPS/NHIS national data to assess specific features of primary care as they relate to use of CRC screening in low-income persons. Local survey findings will also help inform development of the proposed intervention to recruit low-income African-Americans from D.C. into CRC screening through primary care. Given the candidate's prior success in recruiting participants from this low-income population, (85% response rate), the proposed phone surveys to collect data for the RCT seem feasible.

C4. Informant Interviews: Through this prior work, the candidate has become increasingly involved with public sector and private non-profit primary care clinics serving Washington D.C.'s "working-poor" residents. In 1998 she conducted key informant interviews with medical directors and key staff from five different public sector and non-profit primary care clinics in D.C. with regard to how to best recruit the populations they serve into cancer prevention and control research. During these and follow-up interviews, the directors and their staff spoke about what they see as the biggest cancer control and prevention needs

.of their clients. They identified one of their biggest challenges to be the recruitment of minority men and women into colorectal cancer early detection. A common theme was the recognition that while breast and cervical cancer screening rates for lower income African-American women are increasing, screening rates for colorectal cancer for both low-income women and men are not. This local experience is consistent with BRFSS trends in screening rates. African-American men who are lower users of primary care, seem to be among the lowest users of cancer screening and prevention activities. Hence, the candidate is interested in extending her research to determine whether the associations found between features of primary care and screening can be validated at the national and local levels for low-income women and men with respect to CRC screening, in order to inform an intervention and local policy.

C5. Pilot Data from Zacchaeus Clinic: To obtain some descriptive pilot data on low-income men, the candidate reviewed 50 charts of older men from Zacchaeus Free Clinic. Using their administrative database, half of the charts were randomly chosen among men who had not had a clinic visit in the past 1½ years; the other half had a clinic visit in the past 1½ years. Colorectal cancer screening, demographic, personal and social history characteristics were abstracted from the chart without recording personal identifiers. Most men were single or living as single, reported earning less than $8000 per year or did not reveal income in the chart. The most common reason for a recent visit to the clinic was for sick-care, rather than for a routine visit or follow-up. Regardless of whether the men were high or low users of clinic services, over 60% of them had at least 4 health conditions listed on their chart problem lists. Screening rates were low: Among men who had a clinic visit in the past 1½ years, 52% had ever had a FOBT, 12% had ever had a sigmoidoscopy. Only 4% had a recent FOBT and 0% had a recent sigmoidoscopy. Compared to men who had not had a visit in the past 1½ year, those with recent visits to the clinic were more likely to have received a recent FOBT, but sigmoidoscopy rates were still low. This suggests that screening rates, especially for sigmoidoscopy, are also low in these low-income men.

C6. Coordinating cancer prevention efforts among Hispanic Primary Care Clinics: The candidate is also involved in "Marketing Cancer Research to Latin Americans" (P.I. Dr. Elmer Huerta at Washington Hospital Center). Through this project, Dr. O'Malley will develop working relationships with additional clinics in the D.C. area that serve Hispanics. If the intervention proposed in this application is successful, the candidate would be in a position to extend it to a Hispanic sample in a future (RO1) proposal.

In sum, this preliminary work demonstrates the candidate's clear focus. The current proposal builds logically on prior findings, and illustrates her potential to become an independent investigator.

D. RESEARCH DESIGN AND METHODS

D1.Overview: Two phases will be described: 1.) Phase I is the analysis of the Medical Expenditure Panel Survey (MEPS)[88] linked with the National Health Interview Survey (NHIS).[89] These linked data provide detailed information on primary care systems and cancer screening utilization for a nationally representative sample. Analyses of MEPS/NHIS will inform the content of the letter used for the intervention in phase 2. They will also inform the content of the surveys used to examine the feasibility and effectiveness of the phase II intervention. 2.) In phase II, a randomized controlled trial, using a personalized invitation intervention, will be designed, implemented and evaluated in a community clinic to assess its impact on CRC screening in low-income persons age 55 and over. The conceptual model described above will guide both phases. We posit that recruitment into primary care through a clinic coordinated letter, targeted to the recipient's stage-of-change with respect to screening, will act in combination with the predisposing, enabling and need characteristics of this population to affect utilization of CRC screening. Figure 3 summarizes the research timeline.

Figure 3: Timeline of Research	Year 1	Year 2	Year 3	Year 4	Year 5
Phase I:					
• Analyses of MEPS[88] linked with NHIS[89]	XXXX	XXXX			
• Write manuscripts summarizing findings from MEPS/NHIS	XX	XXXX			
• Present MEPS findings in a forum accessible to policy makers.		X	XX		
• Prepare focus group moderator guide	X				
• Identify and hire moderators	X				
Phase II:					
• Conduct Focus Groups with men and women		X			
• Transcribe focus group audio-tapes		XX			
• Analyze transcripts		XX			
• Write manuscript summarizing focus groups		X			
• Design/Refine Zacchaeus Clinic Intervention		XX			
• Design Baseline & Follow-up phone surveys		XX			
• Compile list of persons age over 55 from the clinic's database		XX			
• Develop Randomization Scheme		X			
• Train research assistant on procedures		XX	XXXX		
• Mail initial passive consent letter w/ postcard			X		
• Base-line telephone interview			XXX		
• Medical record release mailing and reimbursements			XXXX		
• Initiate Intervention-Mail letters			XX		
• Process evaluation of intervention via phone call			XXX		
• Monitor # letter recipients who have had a visit since letter			XX		
• 2nd letter mailed to non-appt. makers (intervention arm only)			XX		
• Prepare data base for data entry; Plan Analyses and papers				XXXX	
• Follow-up telephone survey (control and intervention arms)				XX	X
• Chart review of the loss-to-follow-ups only				XX	X
• Key informant interviews of clinic staff re: intervention					X
• Data entry and cleaning				XX	XX
• Analyses of Intervention data					XXX
• Prepare RO1 submission				XX	X
• Present Results to the Clinic Staff & Community Advisors					XX
• Finalize manuscripts summarizing RCT findings					XXXX

D2. Phase I: Analyses of Medical Expenditure Panel Survey and National Health Interview Surveys

D2.1. Description of the MEPS / NHIS surveys and dataset: The Medical Expenditure Panel Survey (MEPS)[88] is the third in a series of nationally representative surveys on health care use, expenditures, sources of payment and insurance coverage for the U.S. civilian noninstitutionalized population. It is consponsored by the Agency for Healthcare Research and Quality and the National Center for Health Statistics (NCHS). MEPS includes surveys of medical and health insurance providers to supplement the data provided by household respondents. The Household Component (HC) of MEPS is designed as a stratified multistage area probability design with disporportionate sampling to facilitate the selection of an over-sample of minorities.[90] The design of MEPS permits person-based estimates. The set of households selected for the 1996 MEPS is a subsample of those participating in the National Health Interview Survey (NHIS).[89] NHIS is an ongoing annual household survey of 42,000 households (109,000 individuals). NCHS conducts NHIS to obtain national estimates on health care utilization including various cancer screening and prevention behaviors, health conditions, health status, insurance coverage and access. Use of the 1995 NHIS in concert with data from the 1996 MEPS permits longitudinal analyses not otherwise available.[91] The Household Component of MEPS in an ongoing annual survey, each panel collects data over a 30-month period to obtain information that covers two consecutive calendar years.

D2.2. Why MEPS/NHIS was chosen for this proposal: MEPS[88] linked with NHIS was chosen for phase I because it is a valuable resource for estimating the impact that changes in health care providers, insurance,

démographic, and other factors have on health care utilization (including cancer screening services) by low-income populations including the elderly, un- and under-insured and racial/ ethnic minorities.[90] It contains an array of the predisposing, enabling and need factors for the proposed model including: demographic and personal characteristics, cancer knowledge, attitudes, beliefs, insurance, and detailed characteristics of primary care systems. Assessment of these factors' associations with CRC screening utilization, will help to identify structural and process barriers and facilitators to screening in the ambulatory care settings. This will inform the second phase of the proposed study. The content of the letter used for the intervention phase can target modifiable barriers consistently identified in the MEPS/NHIS analyses. Findings will also inform the content of baseline and follow-up phone surveys used to assess the intervention. In addition, the scope and depth of MEPS can be used to provide national estimates to aid formulation and analysis of national health policies pertinent to cancer prevention and control. This is especially relevant given that one of the candidate's objectives is the translation of cancer control research into a format accessible to policy makers.

D2.3. Measures: The following measures will be used in analyses examining hypotheses 1a and 1b.

D2.3.1. Outcome Measures: CRC screening utilization will be the primary dependent variable. For FOBT and sigmoidoscopy, rates will be calculated for "ever," "recent" and "adherent" use. The data for these variables will come from the NHIS data. The NHIS survey asks about ever, recent and total lifetime use of the screening tests. It also asks about whether the most recent test was done for routine/screening reasons. Adherence will be estimated as a combination of receipt of a recent routine test plus whether the total lifetime number obtained is appropriate based on age and screening recommendations.[92, 120]

D2.3.2 Independent Variables:
Enabling Factors: The primary independent variables of interest are those related to the structure and process of primary care (presented below). Information on perceived barriers to each of these features comes from the respondents' answers to items on MEPS/NHIS about each feature. Responses (to MEPS/NHIS survey items) reflect the extent to which a respondent perceives each of these features of primary care as being present in his or her usual source of care.

Features of Primary Care: Numerous items from the household and provider components of MEPS and from NHIS assess particular aspects of primary care. These include: **A) Comprehensiveness,** defined as a: "Primary care facility must be able to arrange for all type of health care services, even those not provided efficiently within the facility. A comprehensive approach must at least involve four steps of the medical process: problem (needs) recognition, diagnosis, management and reassessment." **B) Coordination** has been defined as the "Provider is capable of integrating all the care that patients receive." **C) Continuity** is "a characteristic that refers to care over time by a single individual or team of health care professionals ("clinician continuity") and to effective and timely communication of health information (events, risks, advice, and patient preferences) ("record continuity"). **D) Accessibility** "refers to the ease with which a patient can initiate an interaction for any health problem with a clinician (e.g., by phone or at a treatment location) and includes efforts to eliminate barriers such as those posed by geography, administrative hurdles, financing, culture and language." Dimensions of access include **geographic accessibility**—the ability to travel tot he primary source of care; **financial accessibility**—costs associated with health care seeking; **organizational accessibility**—factors related to arranging encounters between patients and physicians (e.g. ability to contact clinic, evening and weekend hours, time to get a sick and well-visit, etc.)[43-45] **E) Patient-Provider Relationship**: Fundamental elements of the ideal physician-patient relationship have been widely studied. Many of these elements are measured in MEPS/NHIS including: communication between the patient and clinician, compassion, trust, perceived competence, and satisfaction with the clinician.[63-64,93-94]

Other Health System Variables: The responses from providers on characteristics of their delivery systems (Provider Component of MEPS) complement the patient self-report from the household component. Thus variables on the type of practice (private office, vs. community health center, vs. other public clinic, vs. and

·managed care arrangements), type of physician (specialty), insurance coverage, conditions diagnosed and services provided are available. Health insurance status will be obtained from MEPS including the presence, type(s), length of and changes in coverage. This will permit subanalyses among the under and uninsured as well as comparisons to insured groups.

Predisposing Factors: Socioeconomic and personal demographic characteristics, age (continuous and categorical, race/ethnicity, income, education, marital status, poverty status (with respect to poverty level), and cancer knowledge, attitudes and beliefs will also be ascertained from a combination of MEPS/NHIS items which use previously validated measures.[88-89,121.]

Need Factors: Health status and comorbidities are measured in both MEPS and NHIS using well validated measures.[88-89, 95-96]

D2.4. Analysis Plan :
D2.4.1 Power: The primary sampling units for NHIS were stratified by geographic area, metropolitan statistical area, and sociodemographic measures. In order to over-sample areas with high population concentrations of blacks and Hispanics, a sample of blocks (segments) was selected within the primary sampling units after being stratified by measures of minority population density. A nationally representative sample of 71,000 addresses within sampled blocks was selected and targeted for further screening to include an oversampling of households of blacks and Hispanics as part of the 1995 NHIS interview. The nationally representative 1995 NHIS subsample selected for the 1996 MEPS consists of 10,597 households completing the series of interviews.[88-89] Five in-person interviews were conducted with each NHIS panel selected for the MEPS-HC over a 30-month field period. Thus this over-sample of the low-income and minority groups provides ample power to conduct analyses between subgroups and to detect the interactions of interest in the analyses.

D2.4.2 Data Analyses: The analysis plan for each hypothesis, and its implications, are discussed below.

Aim 1. (Phase I): To analyze the Medical Expenditure Panel Survey linked with the National Health Interview Survey to test the following hypotheses:

Hypothesis 1a: Lower use of colorectal cancer screening will be associated with less organizational access to primary care; and more personal barriers to screening. This effect will be stronger among low-income men than low-income women.

For hypothesis 1a, the main independent variable is organizational access to primary care. This analysis will include examination for a potential interaction between personal barriers (e.g. competing demands) and the organizational access of the clinic. The effect of personal barriers on receipt of CRC screening may be modified by a more accessible clinic organization. So people may be more likely to obtain screening if for example, they can come for weekend or evening hours, or if front-desk seems approachable). Whereas, those who already have many personal barriers to screening, as well as low organizational access at their usual source of care, may be easily discouraged from seeking screening.

Another example subanalysis of this hypothesis will be to assess for an interaction between gender and organizational access. The candidate hypothesizes that men, who already use ambulatory care at lower rates than women,[97-98] will be even less likely (than women) to get screened if their clinics are not easily accessible.

Univariate, bivariate and stratified analyses using x^2 tests and t-tests as appropriate, will be done to thoroughly assess relationships between the main independent and outcome variables. Assessment for confounding and interaction will be done. To analyze our main outcome measures (recent and lifetime adherence to FOBT and sigmoidoscopy) we will create dichotomous outcome variables (adherent vs. non-adherent) to be analyzed in a multivariate logistic regression framework. A continuous variable (proportion adherent) will also be

·created, and analyzed in multivariate linear regressions.   The lifetime adherence variable may also be measured as an anchored, Likert scaled score reflecting level of adherence. This score would be analyzed as a dependent variable in a linear regression framework. In addition, the conceptual framework depicted in the 'background' section, has feedback loops ("endogeneity," "reciprocity") because individual characteristics influence screening utilization and vice versa. This is especially relevant for provider-related variables such as presence of a usual source of care, which can have a reciprocal relationship with utilization; therefore, structural equation models or simultaneous equations may be necessary to obtain unbiased and consistent estimates.[99-100] In addition to analysis using the conventional multivariate regression approach, models will be analyzed using 2-stage least squares methods (or LISREL).

Variance Estimation: The complex sampling design of MEPS results in departures from the assumptions of simple random sampling. In order to obtain accurate standard error estimates, special methods are required. including the Taylor-series linearization method. MEPS public use files include variables necessary for implementing a Taylor-series variance estimation approach. Software packages[101] appropriate for calculating variance estimates compliment the SAS programming package to be used by the PI.

Implications: If organizational barriers measured in MEPS/NHIS such as the hours of clinic operation and geographic location, are associated with receipt of CRC screening, then the content of the letter for the Phase II intervention will address this issue. For example the letter, which will be reviewed by the patient focus groups, will mention the clinic hours (includes evening and weekend hours) and its convenient location on the bus/metro (greenline). If knowledge barriers are associated with screening in MEPS/NHIS analyses, then the letter will address issues related to knowledge of CRC screening, e.g. myths, being asymptomatic. Findings will also inform the content of baseline and follow-up surveys to assess the Phase II intervention. If, for example, analyses of MEPS/NHIS identify certain barriers to primary care and screening, the surveys can also query about these variables to test for associations with receipt of screening in phase II. Finally, findings will be presented to policy makers in conjunction with the independent study done with Dr. Feder. This will take the form of informational pieces directed to policy meetings or journals.

Hypothesis 1b: Particular features of primary care (*comprehensiveness of services. continuity with a specific clinician,* and *the patient-clinician relationship*) will be more strongly associated with adherence to colorectal screening for lower- than for upper-income persons, regardless of insurance status.

Since MEPS/NHIS samples households throughout the range of incomes, with an over-sample of lower income and minority households, it presents a unique opportunity to identify how the structure and process of primary care may facilitate screening differently for lower vs. higher SES persons. The analytic methods used to investigate hypothesis 1b are similar to those described for 1a. In addition, parallel analyses will be done outside of a multivariate regression framework. This alternate model to be developed will assess the "multiple vulnerabilities" of the population of interest and how the specific features of primary care may be associated with receipt of screening for different groups of respondents. For example, rather than "controlling" for SES, low-income African-American women with insurance, might be compared to middle-income African-American women with insurance with respect to their use of screening.

Implications: If the presence of a stronger patient-physician relationship predicts screening in the MEPS/NHIS data, then the Phase II intervention letter might be individually signed by the clinician last seen by the subject. The need for this would also be examined via the focus groups. If comprehensiveness of services is associated with receipt of timely screening in the MEPS/NHIS data, then the letter might mention that Zacchaeus clinic offers a variety of health as well as social and legal services. Findings will also inform development of the baseline and follow-up surveys to assess the intervention in phase II.

If *clinician continuity,* and *the patient-clinician relationship are* more strongly associated with CRC screening for low- than for upper-income persons, regardless of insurance status. this has implications for the structure of ambulatory systems serving low-income populations. Perhaps Medicaid and Medicare's reimbursement could build-in an incentive for plans to structure service delivery in a way that enhances continuity and hence facilitates receipt of screening and possibly other needed services.

D2.5 Strengths and Weaknesses of Phase I Design: Strengths include nationally representative data over-sampled for African-Americans, and the richness of cancer screening and primary care variables. One limitation is the self-report nature of screening in the surveys.[102-103] It is possible that the degree of over-reporting may vary by SES. While CRC screening is not part of the provider component of MEPS, other utilization variables are included in both the household and provider components. Self-report utilization of these other services will be validated with the provider component for lower and higher SES groups to determine the degree to which over-reporting of other health services varies by SES. The usual limitation of the cross-sectional nature of the NHIS is less of a problem in this proposal. Since MEPS 1996 can be linked with the 5 in-person interviews from each NHIS panel selected, longitudinal analyses are possible.

D3. Phase II: Overview of the Intervention (Years 2-5): This RCT will test the feasibility, acceptability and costs of an intervention to recruit lower income persons age 55 and over into colorectal cancer screening coordinated through primary care. Interventions in this setting need to be mindful of the limited resources of non-profit clinics and the implications this has for the intervention's complexity and sustainability. This proposal focuses on a feasibility study of clinic-directed personalized letter to patients, targeted to their stage-of change (assessed at baseline) with respect to CRC screening. Figure 4 summarizes the RCT. It is estimated that 1028 general introductory letters will need to be mailed to persons age 55 and over (listed in the clinic's database) in order to obtain the final 360 enrollees completing a 1-year of follow-up. Screening for exclusion criteria will be done at the baseline phone interview. Expected percentages of respondents excluded on this screen, and estimated response rates for each step of the study, are presented on the right. To avoid non-specific attention effects, both arms will be contacted the same number of times.

Figure 4. Randomized Controlled Trial

Control Group	Intervention Group	Total N (includes both arms)
Mailed general letter about study w/ postcard Passive Consent +	Mailed general letter about study w/ postcard Passive Consent +	**1028** 10% refuse | **(925)** |
Baseline: Phone Interview Med. chart release mailed	Baseline: Phone Interview Med. chart release mailed	25% refuse call **(694)** 20% excluded on Phone screen **(555)** | 90% return medical record release: Randomize these **(500)**
Mailing of: One-page brochure on colorectal cancer screening	Mailing of: One-page brochure on colorectal cancer screening + **Personalized letter from the clinic targeted to patient's stage-of-change**	
2-week phone call for process evaluation	2-week phone call for process evaluation	10% refuse **450 complete process** ▼ 20% lost to f/u ▼
At 1-year follow-up: Phone interview Chart review of lost to follow-ups	At 1-year follow-up: Phone interview Chart review of lost to follow-ups	**360** complete 1-yr f/u

D3.1 Limitations and Strengths of the Phase II design include: 1.) A potential change in CRC screening recommendations in the next five years, 2.) The focus of this intervention on one clinic site, and 3.) The possibility of lower response rates than anticipated. Plans to address each concern are discussed below.

In the future, colonoscopy might possibly become the preferred screening recommendation over flexible sigmoidoscopy. Given recent evidence,[104-105] colonoscopy is a more comprehensive evaluation for CRC than flexible sigmoidoscopy and FOBT alone, which may not identify proximal cancers. Should guideline recommendations change from flexible sigmoidoscopies to colonoscopies by year two of the KO7, the outcome measure will reflect this change, including colonoscopy as the standard for routine screening.[27] Another potential concern is the RCT's external validity given that it is being done in one clinic. Since this is a pilot RCT to assess the feasibility of the intervention, it may not be completely generalizable to other clinics. However, the intervention will be informed by nationally representative data on low-income minority persons and their community primary care sites. This will increase the relevance of the project to those outside of Zacchaeus clinic. To test the intervention in multiple sites, an RO1 will be planned. Another limitation is the possibility of lower response rates than anticipated. Since this is a feasibility study, we will still be able to report valuable information on the process of the intervention. In addition, the collection of multiple variables on patients' experiences with specific aspects of primary care and with screening will permit useful analyses on the linkages between the structure and process of primary care and receipt of timely screening. All of this information will be useful in informing a future intervention for this population. However, since the PI was able to obtain an 85% response rate for a population-based survey done in a similar population, we anticipate having enough participants to assess effectiveness.

Overall, the strengths of the study design outweigh its potential limitations. It focuses on low-income African-Americans through an inreach intervention to promote CRC screening. This has been identified as a need by local providers. The intervention has the support of the primary care clinic medical director, (letter of support in appendix) and the clinic has flexible sigmoidoscopy capability. Based on prior research we know that letters are relatively low-cost interventions; this is important for sustainability in resource-constrained clinics. In addition, the study will "give-back to the community" by thanking the participants with grocery store coupons as well as presenting the study findings to the clinic directors and community advisors. Hence the proposed course of study will contribute to the field by providing data to aid the planning of future primary care cancer control interventions. We are theorizing that this intervention would: 1.) Give the issue (CRC screening) credibility and legitimacy since the information is coming from a health care provider which the patient has sought out in the past for care (enhancing continuity and capitalizing on the increased trust of a provider with whom one is familiar); 2.) Reduce barriers to receipt of screening by for example, informing the patient of weekend and evening hours and inviting the client in for care (organizational accessibility); and, 3.) Focus intervention and clinic resources on a captive audience known to be nonadherent to screening.

D3.2 Focus groups: Members of the target population will be involved in the planning efforts[106] for this study through focus group participation. Recruitment for the focus groups will be via posters in the waiting room of the medical clinic and throughout Zacchaeus's facilities. This method has been used successfully in the past by the candidate. One focus group of male patients age 55 and over and one focus group of female patients age 55 and over will be conducted by experienced, culturally sensitive, age and gender-appropriate moderators and assistants. Focus groups will occur in a neutral neighborhood setting. Focus group feedback will be enlisted on a draft personalized letter-invitation and on experiences with facilitators and barriers to recruitment and receipt of colorectal cancer screening. The focus groups will also probe about how best to frame the base-line and follow-up telephone surveys, and how to reach the target population for survey administration. The moderator guide for this focus group will be informed by phase I analyses, prior focus groups in a similar population, and from the literature.[107] Respondents will be receive a $25 grocery store coupon in appreciation for their participation. Focus groups will be audio-taped, transcribed verbatim and analyzed by the PI and two other coders. Analysis of transcripts will be

, based on grounded theory.[108-109] Coders will review the transcripts independently and mark each separate unit of text. Units of text will then be intuitively coded separately by each reviewer. Reviewers will then categorize the units of text by thematic codes and compare their findings. Together they will develop a taxonomy of agreed upon codes through an iterative process. Each will then recode his/her transcripts using these codes. Inter-rater reliability will then be calculated. Once areas of discrepancy are noted, they will be discussed with the focus group moderators. (Moderators will be two of the coders). Content of the letters for the phase II intervention will reflect the most frequently mentioned themes.

D3.3. Details on the Randomized Controlled Trial:

D3.3.1 Intervention site: Zacchaeus Free Clinic is a primary care clinic that provides free care to low-income, predominantly African-American, residents of Washington, D.C.. It has a full staff of primary care providers as well as equipment and a room for the performance of flexible sigmoidoscopy. This clinic has a long history in Washington, D.C. and is situated within Bread for the City—Zacchaeus Free Clinic complex on 7th Street on metro and bus lines. In addition to primary medical care for low-income persons, this complex provides professional legal counsel, social services, nutrition counseling, health education and free clothing and groceries to low income people in D.C. The primary care clinic has evening and weekend hours. The clinic is open to all persons, regardless of where they live in D.C.

D3.3.2 Study Population: Lower income persons, age 55 and over, enrolled at Zacchaeus clinic. In the past six months alone, their primary care clinic received visits from 540 unique uninsured patients over the age of 55. From their computer database we know that there are over 2500 African-Americans age 55 and over with at least 1 visit in the past 3 years.

Exclusion criteria: Has a current diagnosis of colorectal cancer *
Undergoing treatment for colorectal cancer*   (*Assessed in baseline phone survey)

Inclusion criteria: Age 55 and over, male or female   (from clinic's Access database)
Has a current address and phone number in the clinic's database
No sigmoidoscopy or colonoscopy in the past five years*

We recognize that patients who had received a sigmoidoscopy/colonoscopy in the five years prior to study entry might not be offered colorectal screening within the follow-up period. Hence, we are limiting participants to those who have not had a sigmoidoscopy in the past five years. To be age eligible for at least one screening sigmoidoscopy, participants will have to be at least 55 years by study entry. Based on our clinic chart review, we are assuming that rates of "ever" having had a sigmoidoscopy will be extremely low, i.e. most patients will not have had one in the past five years. Thus there is a large base from which to sample. For these patients a sigmoidoscopy would be indicated in the 1-yr follow-up. [32, 110]

D3.3.3 Patient Recruitment and Retention: Using Zacchaeus Free Clinic's computerized (Microsoft Access) database, all women and men age 55 and over with at least one visit in the past five years will be identified. A random sample of patients will be randomly selected from this list (Further discussion follows in sections on sample size and response rates.) To optimize retention and recruitment, respondents will receive a $20 grocery store coupon for completing the baseline phone survey and medical record release. They will also receive a $20 grocery store coupon upon completion of the follow-up phone survey.

D3.3.3 Randomization: Individuals who complete the baseline phone interview and medical release form will be randomized. Patients will be randomized (using a random numbers table) to either control or intervention group. In an attempt to obtain similar numbers of men and women, randomization will be stratified on gender. Because "presence of a doctor visit in the past year" is such a strong predictor of the receipt of FOBT, we are considering doing a stratified blocked randomization around this variable. This technique will assure that this predictor of screening-use is evenly distributed among arms.[111]

D3.3.4 Consent: For the focus groups, a letter of consent will be read aloud and reviewed for signature at the beginning of the each session. For the RCT, a general information letter about the study will be sent to all potential respondents, without mention of CRC. The letter will include a stamped addressed postcard to the PI which the respondent will be asked to return if s/he does NOT want to be contacted in the near future for a phone interview (passive consent). Persons who do not return the card will be phoned for the baseline survey. Verbal consent will be obtained by phone. Respondents from both arms will receive a follow-up mailing containing a medical record release to sign. (Chart reviews will only be done for Zacchaeus patients who get randomized but are later lost-to-follow-up).

D3.3.5 Response Rate: It is difficult to find published response rates to personalized letters among lower income African-Americans in the literature. In insured middle class populations, response rates invitations to screening range from 27% to about 45%.[87, 112-114] Data from a cancer prevention program administrator in Washington D.C. found that letters received a much higher response rate (a 10% increase) among low-income older persons if they were sent by a physician rather than by a lay person. (Unpublished data, personal communication with Barbara Baldwin, D.C. Dept.of Health.)

We have conservatively estimated the response rates at each stage of the RCT (Figure 4). We assume that 10% of people who receive the passive consent post-card with the general introductory letter, will return the postcard asking not to be contacted further. We then assume that 25% of persons called will refuse to respond to the baseline phone survey. The candidate's population-based phone survey in a low-income population in D.C. (where no prior letter was sent) obtained an 85% response rate.[115] So, we feel that in this clinic based setting, response of 75% to the phone interview is a conservative assumption. Then we assume that through the phone screening, 20% of persons will not be eligible for participation. This includes persons with colon cancer (1-2%), and persons who have had a sigmoidoscopy in the past five years. Of those who complete the phone interview, we assume that 90% will also return the chart release. There is an incentive of a $20 certificate for groceries for return of this form. This leaves an anticipated 500 persons will then be randomized to either control or intervention arm. Of these, we assume 10% will refuse the 2-week process phone call after the mailing. We then assume a 20% loss-to-follow-up among these 450 persons. Again, a $20 incentive is provided for completion of the follow-up phone survey.[116] In sum, in order to have 360 persons complete this study through 1-year follow-up, we anticipate needing to mail 1028 introductory general letters with passive consent reply.

D3.3.6 Gender and Minority Inclusion: This proposal focuses on black/African-American women and men from low-income areas. This population was chosen because they suffer from disproportionate colorectal cancer morbidity and mortality. For the intervention phase of the proposal, the focus group participants (16 black/African-American men and women) will be recruited through flyers posted in and around a nonprofit primary care clinic serving low-income persons in Washington, D.C. For the inreach intervention. 360 low-income black/African-American men and women will be recruited through clinic-letters to patients enrolled in the clinic database who are non-adherent to colorectal cancer screening.

Focus Groups	Black/African-American	Total
Female	8	8
Male	8	8
Total		16

In-reach intervention:	Black/African-American	Total
Female	180	180
Male	180	180
Total		360

D3.3.7 Participation of Children: Children are not included in this proposal because the disease and the screening tests of concern are not of relevance to this population.

D3.3.8 Intervention: Upon completion of the phone interview, the intervention group will be mailed a one page information pamphlet with a culture- and gender- appropriate graphic of a man or woman and information on colorectal cancer screening, as well as a personalized letter inviting them in for screening and a primary care visit. The letter will be on Zacchaeus Clinic stationary and will be personalized to the respondent's name and mailed to their current address as listed in the clinic's database. Based on the patient's stage-of-change [51-52] (identified in baseline phone interview) toward CRC screening, the letter will be framed as appropriate for the respondent's current stage. Different versions of the letter will exist for each of the stages-of-change from the Transtheoretical model. Both documents will be readable at a 6th grade level. Members of the intervention arm who have not called the clinic for an appointment within 1 month of the first letter, will receive a 2nd letter. Controls will receive the pamphlet, but no letter.

D3.3.9 Data collection: At baseline and at follow-up, data will be extracted from the clinic's electronic appointment database, including updated demographic and contact information. Baseline phone surveys will occur for all consenting patients. For intervention and control participants phone surveys will also occur at the 1-year follow-up. The following figure (5) summarizes the points at which each variable will be collected. To ensure that the format for identifying screening utilization is consistent across those who use Zacchaeus clinic during the 1-year follow-up, and those who go elsewhere, data will be obtained via self-report from the follow-up phone surveys. Baseline and follow-up phone surveys will collect information on demographics, colorectal screening, co-morbidities, visit history, experiences with primary care, perceptions of the clinic's accessibility, their continuity with a clinician, perceptions of the comprehensiveness of services, of the patient-clinician relationship, and of the coordination of their care at the clinic. It will also ask about receipt of cancer screening outside of the clinic during the study period. While studies have established that self-report usually overestimates use.[102-103] the tendency for over-reporting should not differ markedly between study arms. It will also ask about reasons for presentation to the clinic during the study period (letter vs other), stage-of-change with respect to CRC screening, and cancer knowledge attitudes and beliefs. Any change in insurance status or other characteristics will be recorded. For the subgroup of respondents reporting an abnormal result, the follow-up procedures and clinical outcomes will also be recorded and assessed with respect to their coordination through the clinic.

For patients who get randomized and enrolled, but who are later lost-to-follow-up, chart review will be done to collect needed variables. An attempt to review all charts of all consenting participants would be beyond the resources provided by the KO7. Furthermore, relying on chart reviews to ascertain screening during the 1-year follow-up would not be feasible for those who seek care outside Zacchaeus clinic.

D3.3.10 Measures: The following measures will be used to assess the hypotheses 2a and 2b.

Overview: For the intervention proposed during years 2-5 of this application, we will have three different measures of screening outcomes: Receipt of FOBT in the 1-year follow-up, receipt of sigmoidoscopy in the 1-yr follow-up, and receipt of both a fecal-occult blood test and a sigmoidoscopy (or colonoscopy) during the 1-year follow-up. (Compliance with FOBT will be defined as return of at least one hemoccult card to the clinic during the one-year period, and compliance with sigmoidoscopy will be defined as receipt of sigmoidoscopy at any time during the 1-year follow-up period. All phone survey measures used will be based on items from previously validated instruments in similar populations.[18,64-65,88-89,115] **Figure 5** summarizes:1.)The outcome (dependent variables), main independent variables and other covariates, 2.)How and when each will be collected, and 3.) How each measure fits into the conceptual framework described in the background section of this proposal. In addition to the screening utilization outcome, an additional outcome will be the patient's stage-of-change (regarding CRC screening) at the follow-up phone interview. Stage-of-change will be compared for control and intervention participants to assess whether there was a difference in progress along the stages associated with receipt of the intervention.

Figure 5. Phase II Measures, Timing of data collection, and Relevance to the Conceptual Model.

Measures	Which Phone Survey		Relevance to Model
	Baseline	Follow-up	
Primary Outcomes:			
FOBT	X	X	Use of Health Services/ Behavior
Sigmoidoscopy/colonoscopy	X	X	Use of Health Services/ Behavior
Both FOBT and Sigmoidoscopy @ 1 year f/u	X	X	Use of Health Services/ Behavior
Stage of Change with respect to CRC screening	X	X	Predisposing characteristic
Process Measures (of the Intervention):			
Made an appointment to be seen at Zacchaeus Clinic or other clinic in the past year		X	Use of Health Services
• % who kept their appointments		X	Will measure to assess the process of
• follow-up of abnormals		X	follow-up
Costs: Staff time, Material production, Postage, Telephone costs	cost protocol		
Patient perceptions of the letter	2-wk process phone call		May be affected by various aspects of the model
Acceptability of the intervention: To patients To clinic staff	2-wk process phone call	Interviews of staff	May be affected by various aspects of the model
Primary Independent Variables:			
Control vs. Intervention status			Study design
Other Independent Variables:			
Specific Features of Primary Care at their clinic:	X		Health Care System- Enabling Characteristics
• Accessibility	X		
• Comprehensiveness of services	X		
• Continuity of care at the site & with clinician	X		
• Coordination of specialty care and tests	X		
• Patient-Physician Relationship			
Insurance status	X	Changes	Enabling Characteristics
Health status/ Comorbidities	X	X	Need
Family history of colorectal cancer	X		Predisposing
Which clinician saw patient at most recent visit	X	X	Enabling
Did patient's regular clinician recommend test?		X	Enabling/Patient-Provider Relationhip
Barriers to use of primary care and CRC	X	X	Predisposing, Environment
Social support	X		Predisposing, Environment
Demographics: Age, Income, Education, etc.	X		Predisposing factors
Knowledge/Attitudes/Beliefs	X	X	Predisposing factors
Reason for receipt of screening in the past year		X	Predisposing, enabling or need
GI symptoms experienced in past year		X	Need

Main Independent Variables: Intervention vs. Control status.

Other Independent Variables of Interest: Other independent variables of interest include measures assessing the process of the intervention (for hypothesis 2a). These include patient and staff perceptions of the acceptability and feasibility of intervention. Costs of the intervention will also be collected according to the cost protocol summarized in the cost-effectiveness section. Figure 5 (above) summarizes the variables of interest for the process evaluation. In addition to assessing the process and effectiveness (hypothesis 2b) of the intervention, the candidate will assess how other independent variables of interest may relate to screening use during the follow-up period. For these analyses, independent variables of interest include: the features of primary care (continuity, comprehensiveness, coordination, accessibility and the patient-provider relationship.) All will be assessed using measures which have been previously administered by phone and evaluated in lower income and minority populations.[65, 88-89, 115]

Additional Controlling variables to be considered in the baseline and follow-up surveys and chart reviews include personal and demographic characteristics: Age, education, income, changes in health insurance status, work and marital status, gender, race/ethnicity, family size, family/social-support (MOS) presence of gastrointestinal symptoms, and a family history of CRC,[34,80] practical conflicts with work or family, inconvenience, cost, and anxiety about health services, preventive health orientation (i.e. engaging in other health behaviors: smoking, diet etc.), knowledge, attitudes and beliefs about cancer.[36-37, 39-42,57,122]

D3.3.11 Data Management—Training, Quality Assurance, Confidentiality and Security: The research assistant will be trained in the issues of data quality, confidentiality and security. Verbal consent will be obtained from phone survey participants, and signature on a clinic and IRB approved medical chart release form will be obtained as well. All data will be stripped of personal identifiers in the database and assigned a respondent I.D. number. Data will be maintained electronically via entry from a CATI system and this data will be kept secure by the P.I. and research assistant. All information provided by respondents will be confidential, no attempts will be made to link respondents to any other databases. When findings are presented in publishable format or as verbal presentations, only group data will be presented.

D3.4. Analysis Plan: This section summarizes study power and the approach to data analysis. Regarding the analysis, control and intervention groups will be assessed for comparability of baseline characteristics as well as for loss to follow-up. If there is differential loss-to-follow up among the randomized participants, then the candidate will perform an **intention-to-treat** analysis.

Power and Sample Size Assumptions: The sample size is based on both recent FOBT and sigmoidoscopy rates, and we will over-sample assuming some participant loss-to-follow-up. Calculation of sample size for the outcomes of a recent FOBT and/or sigmoidoscopy is complicated by the fact that estimates of screening rates vary widely within and between datasets, between reporting-years, by wording of items on screening, by self-report vs. chart review rates, and by sample characteristics. National data indicate that 20% of persons over age 50 have had FOBT (in the last year), and 30% have had a sigmoidoscopy/proctoscopy (past 5 years).[29] Among African-Americans over the age of 50 in Washington, D.C., rates of recent FOBT (in the past year) rates are 0% vs. 45% for lower vs. higher income African-American men, and 22% vs. 24% for lower vs. higher income African-American women.[30] Approximately 7% of low-income African-Americans in D.C. reported "recent" receipt of both FOBT (past year) and sigmoidoscopy (past 5 years).[30]

Power: To calculate power for this study, we conservatively assume that rates of having both screening tests will range from 5-20% in the control group. This is based on the extremely low rates for both FOBT and for sigmoidoscopy found in low-income (< $20,000 per household) African-Americans in the D.C. BRFSS data as well as from the pilot chart-review data at Zacchaeus Clinic. Sample size calculation will be based on the primary outcome measure, **recent receipt of both FOBT and sigmoidoscopy.** To be conservative, we will calculate a sample size that would detect at least a 10% effect.

Table 1. Range of Sample Size Calculations with Varied Assumptions:

α	β	P_1/P_2 (Effect Size) P_1 is receipt of BOTH a recent FOBT and sigmoidoscopy rate in controls P_2 is receipt of BOTH a recent FOBT and sigmoidoscopy rate in tx group	Sample Size per arm	Total number needed (Including cushion for loss-to-follow-up)
.05	.20	.05/.15 (.10)	110	300
.05	**.20**	**.10/.20 (.10)**	**156**	**360**
.05	.20	.20/.30 (.10)	231	500

As seen in above, for analyses where the dependent variable is receipt of "both FOBT and sigmoidoscopy", a sample size of 360 will provide power of at least 80% at the .05 (one-sided test)

significance level to detect differences of 10% or greater between intervention and control arms.[117-118] This assumes a baseline rate of "recent" screening for **both** FOBT and sigmoidoscopy combined, of 10% or lower.[30] Given the low-baseline rates of screening in this population,[30] this sample size will also provide adequate power (80% at the .05 significance level) to detect differences of 10% or greater between arms when the outcome is "recent FOBT" alone (dichotomous) or "recent-sigmoidoscopy" alone.[117-118]

Analysis Plan for the Intervention Study: Analysis plans for each hypothesis are summarized below.

Aim 2. To test the feasibility, acceptability, preliminary effectiveness and costs of a simple letter intervention in a community-based clinic.

Hypothesis 2a. Personalized tailored letters, targeting a patient's stage-of-change with respect to colorectal cancer screening, will be a feasible and acceptable intervention to clinic staff and patients of the primary care clinic. (*process* evaluation)

A process evaluation will be done to assess the acceptability of the intervention from the perspective of patients (2-weeks) after the mailings. To avoid non-specific attention effects, controls will also be called, but CRC screening will not be mentioned. Process evaluation will also be conducted in the clinic staff via key informant interviews. Included in the questions for the clinic staff will be how abnormal FOBTs and sigmoidoscopies will be referred out for evaluation. The clinic currently has specialists and hospitals to which it refers, however, ground-work for larger scale referrals for a future intervention, will be laid.

Process Outcome Measures: Two weeks after the mailing of the letter intervention, participants in both arms will be called to assess their receipt of the mailing. The intervention group will be asked: whether they received the letter, whether they opened it (why or why not), if they read the letter, how long it took to read, clarity, reactions to the letter, what they liked and disliked about the letter, and suggestions for changes. A knowledge question will also be included to assess whether the recipient read the letter. Other process measures are outlined in the above figure. They will include the acceptability of the intervention to clinic staff and patients. Key informant interviews will assess acceptability from the staff perspective.

Cost and cost-effectiveness of the intervention: Advised by her mentor, Dr. Mandelblatt, who has expertise in cost-effectiveness analyses the candidate will develop a cost-tracking protocol. This protocol will measure staff time, material production costs, postage, telephone costs and will categorize costs as either research and development or implementation. Examples of research and development costs include the time to develop and review patient materials and instruments, meetings to finalize instruments, research assistant travel and oversight, and data entry. Implementation costs include the time spent sending tailored messages, and mailings. Effectiveness of the intervention will be measured as the incremental number of patients receiving screening during the follow-up period. Additional costs will include patient time spent in phone screening or receiving the intervention. We will directly measure the time spent by patients and care givers, since these may vary across the intervention arms. Main analyses will only consider implementation costs, since these are the costs borne by providers adopting the intervention.

Hypothesis 2b: Personalized tailored letter-invitations will be *effective* in motivating patients to obtain colorectal cancer screening (FOBT and flexible sigmoidoscopy) within the 1-year follow-up.

Variables for analysis of hypothesis 2b have already been summarized in Figure 5 and the measures section. Participants will be compared to non-participants. Using the predisposing, enabling and need variables identified in the phone surveys, control and intervention groups will be assessed for comparability of baseline characteristics as well as for loss to follow-up. If there is differential loss-to-follow up among the randomized participants, then the candidate will perform an **intention-to-treat** analysis. The comparability of the sample to the overall low-income population age 55 and over, will be made using Census data. Outcome measures (Figure 5) will be compared for control and treatment groups

using various analytic techniques, including simple comparisons of proportions screened. We will also measure the number of doctor visits to Zacchaeus clinic and to alternate health care sites during the 1-year follow-up period. Indicators of treatment adherence will include: number of patients in each group who received the cancer screening tests (FOBT/ sigmoidoscopy) in the 1-yr follow-up. Multivariate analyses will be conducted using baseline characteristics to provide adjusted treatment comparisons. For the main multivariate regression models, the dependent variable of interest will be dichotomous, i.e. timely use of FOBT and sigmoidoscopy within the 1-year follow-up.

D4. Dissemination of Findings and Implications for Future Work: A long-term career objective is to develop the skills and relationships with providers and community representatives to promote primary care cancer control interventions in a way that allows them to be self-sustaining. To this end, the candidate's local findings will be shared with relevant parties including clinic staff, community representatives, and local policy makers in appropriate forums. For example, the results will be presented at a Zacchaeus clinic staff-meeting. At the local policy level, the person responsible for screening programs in the D.C. Health Department will be approached and asked if findings can be presented. The candidate has already shared prior findings on breast and cervical cancer screening with local providers in Washington D.C. In addition, an RO1 intervention will be written in year 4 of the proposed KO7. This RO1 will incorporate multiple sites and will assess adherence to CRC screening for low-income persons throughout the D.C. metro area.

D5. FINAL SUMMARY: At both national and local levels, lower-income African-Americans suffer disproportionately from colorectal cancer. Limitations in access to early detection and primary care explain some of this disparity. This proposal uses the behavioral model adapted to incorporate vulnerable populations and a primary care framework. Using this model, the candidate will analyze national data to identify *predisposing, enabling* (including characteristics of primary care) *and need* factors associated with low-income minority persons' use of colorectal cancer screening. Then, an intervention targeting low-income clinic enrollees who are nonadherent to screening, will be conducted. Few prior interventions have addressed the needs of <u>low-income women and men</u> with respect to the receipt of a <u>clinic originated personalized invitation, targeted to the patient's stage-of-change</u> for <u>colorectal cancer screening</u>.

This proposal focuses on a need identified by both the NCI Strategic Plan to Reduce Health Disparities, and by local providers working directly with the population of interest. It is unique in its focus on CRC screening in low-income African-Americans, including men, an understudied group. Its focus on characteristics of community-based primary care is innovative. It's use of national and local data are complementary: it extends the candidate's prior local findings via analysis of nationally representative data; then, national data on facilitators and barriers to CRC screening will be used to inform the content of the local intervention. It uses a comprehensive theoretical framework to drive design, data collection, analyses and interpretation of policy relevant results.

The course of study outlined by this application includes *didactic training* (in analysis of nationally representative data, randomized controlled trials, program evaluation and health policy), *research experience* (analyzing national data and conducting an inreach screening intervention) and *real-world training* in the translation of cancer control research into practice. Under the guidance of experienced mentors in a supportive institutional environment, pursuit of this integrated research and training experience will enable the candidate to transition to fully independent cancer control investigator.

Ultimately, with skills gained through this KO7, the candidate would like to extend the proposed intervention to a broader population of low-income persons to promote adherence to colorectal cancer screening recommendations. In the long-term, the candidate would like to work with community clinics to facilitate development of the infrastructure necessary to provide evidence-based cancer screening and follow-up services coordinated through primary care. The applicant's proposal has potential to improve the overall delivery of cancer early detection services to a population that suffers disproportionately from potentially avoidable cancer morbidity and mortality.

E. Human Subjects

This proposal focuses on a feasibility study of clinic-directed personalized letter to patients targeted to their stage-of change with respect to colorectal screening (assessed at baseline). The goal of the intervention is to recruit lower income persons age 55 and over into colorectal cancer screening coordinated through their usual source of primary care. It is estimated that 1028 general introductory letters will need to be mailed to persons age 55 and over (listed in the clinic's *Access* data-base) in order to obtain the final 360 enrollees completing a full 1-year of follow-up. (Details summarized in the Methods section of the proposal) Screening for exclusion criteria (current diagnosis or treatment for colon cancer) will be done at the baseline phone interview. Persons with colorectal cancer will be excluded from the study.

An IRB-approved letter of consent will be obtained from participants of the focus groups. An IRB-approved verbal consent will be obtained for both phone interviews. A medical chart release form will be obtained from enrollees prior to review of charts. Charts will only be reviewed for those who are lost-to-follow-up for comparative research purposes. All data will be kept confidential. No attempt will ever be made to tie findings to a particular respondent. Data will be reported in publishable form for the group as a whole.

Most of the data is self-reported by the respondents. The data is being collected for research purposes. Georgetown University's IRB has authorized the informed consent procedures for this study. All data will be maintained and analyzed by the P.I. in her office at Georgetown University Medical Center. All reports of the data will be in aggregate.

As the only intervention is a mailed letter, subjects are unlikely to experience adverse risks other than the use of the time it takes to read the letter and complete the telephone interviews, estimated at less than 15 minutes each.

F. Vertebrate Animals: Not applicable.

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From: sgim@cos.com
To: <omalleya@georgetown.edu>
Date: 2/28/01 12:56PM
Subject: SGIM Annual Meeting Submission Acceptance

Dear Dr. O'MALLEY,

We are pleased to inform you that your submission to the SGIM - 24th Annual Meeting entitled PRIMARY CARE DELIVERY AND LOW-INCOME WOMEN'S ADHERENCE TO CANCER SCREENING, has been accepted for presentation in an oral abstract session. Another email message, including scheduling information, will be sent within two weeks.

Your presentation will be limited to 10 minutes, followed by 5 minutes of questions and discussion. To be fair to all presenters, the session moderators will strictly enforce the 10-minute limit. A slide projector will be available for your use during the session.

If for some reason you already know that you cannot attend the meeting in San Diego, please email an immediate reply to withdraw your abstract from the schedule. Otherwise, we will expect to see you in San Diego. Preliminary programs, including registration information and forms, will be mailed this week.

Conference headquarters will be at the Sheraton San Diego Hotel and Marina. You are welcome to make reservations; their toll free phone number is 877/734-2726. SGIM has negotiated group room rates beginning at $192 single and $212 double.

Thank you for your submission. We look forward to a successful annual meeting.

Eliseo Stable-Perez, MD
Chair
Scientific Abstracts
and
Rodney Hayward, MD
Co-Chair
Scientific Abstracts

Academy Annual Meeting

June 10-12, 2001 ☐ Atlanta Hyatt

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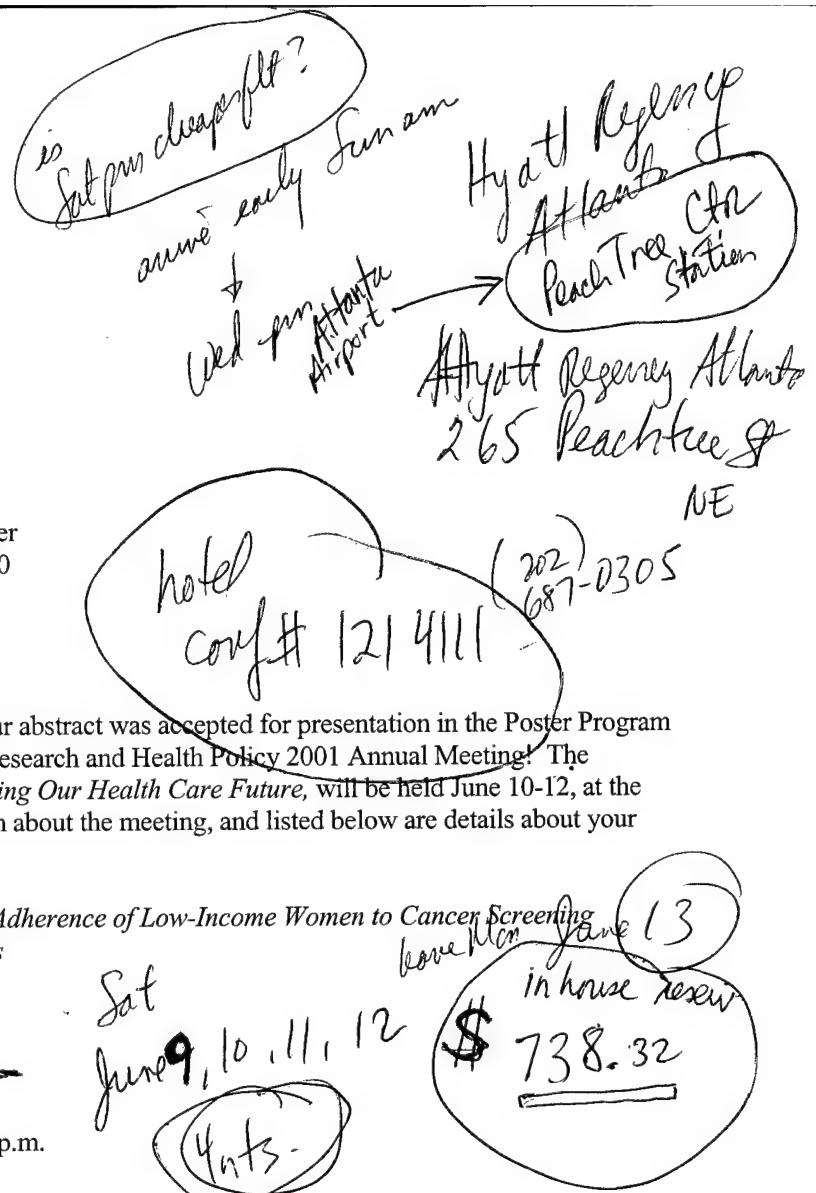
March 12, 2001

Ann S. O'Malley, MD, MPH
assistant professor
Oncology/Medicine
Georgetown University Medical Center
2233 Wisconsin Ave., N.W., Suite 440
Washington, DC 20007

Dear Dr. O'Malley:

We are pleased to inform you that your abstract was accepted for presentation in the Poster Program at the Academy for Health Services Research and Health Policy 2001 Annual Meeting! The conference, *Research to Action: Shaping Our Health Care Future,* will be held June 10-12, at the Atlanta Hyatt. Enclosed is information about the meeting, and listed below are details about your poster session.

Abstract Title: *Primary Care & Adherence of Low-Income Women to Cancer Screening Recommendations*

Poster Session: A

Date: Sunday, June 10

Time: 11:45 a.m. - 1:15 p.m.

Location: Exhibit Hall

During the 90-minute poster session, authors will stand by their 4'x8' poster board displays to answer questions and discuss methods and findings. Before the meeting, you will be assigned a poster board number. Abstracts of all posters presented at the conference will be distributed to conference participants in CD-ROM format and posted on the Academy website before the meeting.

Enclosed is the conference brochure with registration information. Please note that poster presenters are required to register for the meeting and do not receive the conference faculty rate. **Please confirm your participation in the Poster Program by Friday, March 30. You may fax the enclosed yellow form to Alice Drew at 202/292-6836 or email Drew@ahsrhp.org**. If we do not hear from you by March 30, we will assume you will not be participating in the poster program.

The Academy's Poster Program has grown in size and recognition over the years. Today it is an integral part of the meeting and an effective mechanism for research dissemination and networking. We appreciate your interest in the conference and hope to see you in June!

Sincerely,

Marian Mankin

Marian Mankin, M.Ed.
Director, Annual Meeting

Academy Annual Meeting

June 10-12, 2001 ⌐ Atlanta Hyatt

March 12, 2001

Ann S. O'Malley, MD, MPH
assistant professor
Oncology/Medicine
Georgetown University Medical Center
2233 Wisconsin Ave., N.W., Suite 440
Washington, DC 20007

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Abstract Title:	*Primary Care Performance and Low-Income Women's Patient-Physician Relationships*
Poster Session:	A
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Sincerely,

Marian Mankin

Marian Mankin, M.Ed.
Director, Annual Meeting

Era of Hope

**Department of Defense
Breast Cancer
Research Program
Meeting**

June 8-11, 2000
Hilton Atlanta
and Towers
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**PROCEEDINGS
Volume II**

The Department of Defense
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FOREWORD

The views expressed in the 2000 Department of Defense (DOD) Breast Cancer Research Program's *Era of Hope* Proceedings are those of the authors and do not necessarily reflect official policies or positions of the U.S. Army Medical Research and Materiel Command, the Department of the Army, the DOD, or the U.S. Government.

In conducting the research described in these Proceedings, the investigators adhered to the *Guide for the Care and Use of Laboratory Animals,* National Research Council, 1996. In addition, research performed under the auspices of the U.S. Government was conducted in compliance with the Animal Welfare Act and other Federal statutes and regulations related to animals and to scientific experiments involving animals.

Investigators conducted their human subjects research in accordance with applicable Federal, DOD, and Army regulations, including Food and Drug Administration (FDA) Regulations 21 Code of Federal Regulations (CFR) 50, 54, 56, 312, 314, 601, 812, and 814; 32 CFR 219; DOD Directive 3216.2; Army Regulation 70-25; and Office of the Army Surgeon General Regulation 15-2.

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MEASURING PATIENT SATISFACTION FOR QUALITY IMPROVEMENT. LE Harris, RW Swindle, SM Mungai, M Weinberger, WM Tierney. Regenstrief Institute, Indiana University School of Medicine, Roudebush VAMC, Indianapolis, IN.

Health care organizations seek patients' ratings of care for both internal quality improvement and external quality reporting. Unfortunately, a single measure to accomplish both purposes has not been reported. We describe the reliability and validity of a visit-specific patient satisfaction instrument that we designed for both purposes.

We surveyed adult and pediatric patients in five university-affiliated primary care sites serving enrollees of six managed care plans. The instrument, administered by mail with telephone follow-up of non-responders, included the 9-item Medical Outcomes Study Visit-Specific Questionnaire, the 12-item American Board of Internal Medicine Patient Satisfaction Questionnaire, and 11 items developed by our Quality Improvement Committee.

Two-thirds of the adult (1,255/1,286) and pediatric (794/1,296) surveys were returned, with less than 5% data missing on all items. In both samples, principal components factor analysis revealed 4 factors: satisfaction with access (ACC), physician (MD), nurses (RN), and office staff (OFF). In both samples, internal consistency was high (Cronbach's alpha > .85). Using multiple logistic regression, satisfaction with ACC, MD, and OFF were all significant (p<.01) predictors of overall satisfaction; satisfaction with RN was significant only for adults (p<.001). These findings were observed when controlling for patient demographics, satisfaction with office wait time, whether the visit was with their regular provider, and type of visit. We also detected significant differences across sites, which served as the basis for developing quality improvement strategies. This visit-specific patient satisfaction instrument is 1) reliable and valid in both adult and pediatric samples and 2) capable of identifying areas for quality improvement.

THE EFFECT OF RACIAL CONCORDANCE BETWEEN PATIENT AND PHYSICIAN ON THE PERCEIVED QUALITY AND ACCESSIBILITY OF HEALTH CARE. S Saha, M Komaromy, and TD Koepsell, Seattle VAMC and University of Washington, Seattle, WA, and UC San Francisco, San Francisco, CA.

Minority populations in the U.S. have lower access to care, use fewer health services, and express less satisfaction with health care than whites, even with similar health insurance coverage. These disparities may in part be due to racial or cultural barriers between health care providers and patients of different backgrounds. We hypothesized that racial concordance between patient and physician is associated with greater patient satisfaction, greater reported use of preventive care, and greater likelihood of receiving health care that is perceived to be necessary.

We analyzed national data from the Commonwealth Fund 1994 Minority Health Survey. Telephone interviews were conducted with 1114 non-Hispanic whites, 1005 non-Hispanic blacks, 1001 Hispanics, and 626 Asians. Of these, 2587 had a regular physician of known race. In logistic regression analyses adjusting for age, sex, education, health status, insurance type, and primary care site, black individuals with black physicians were more likely than those with other-race physicians to rate their doctors as excellent (OR 2.2, 95% C.I. 1.5-3.3), to report receiving preventive care (OR 1.7, 95% C.I. 1.0-3.0), and to report always receiving care that they felt they needed (OR 2.6, 95% C.I. 1.1-6.0). Hispanic respondents with Hispanic physicians were more likely to be very satisfied with their health care services overall (OR 1.6, 95% C.I. 1.0-2.5). Further adjustment for income, primary language, access barriers, and patients' ability to choose their physician did not substantially change these results. Physician-patient racial concordance among whites and Asians was not significantly associated with any of our response variables.

Our findings reaffirm the role of minority physicians in providing health care for minority populations and the importance of continuing efforts to recruit underrepresented minorities into the medical professions. Further studies aimed at improving our understanding of potential racial and cultural barriers between patients and physicians are warranted.

SPECIAL OR VULNERABLE POPULATIONS

NAVAJO USE OF NATIVE HEALERS. C Kim, Y Kwok, and B Muneta, Crownpoint Healthcare Facility, Crownpoint, NM, Indian Health Services Headquarters West, Window Rock AZ.

Context. The interaction of Navajo native healers, or medicine men, with conventional medicine has not been researched, although the Indian Health Service provides extensive health care service to this population.
Objectives. To determine the prevalence of native healer use, reasons for use, cost of use, and the nature of any conflict with conventional medicine.
Design. Survey conducted by two physicians.
Setting. Rural Indian Health Service hospital in New Mexico.
Patients. Consecutive sample of 300 Navajo patients in ambulatory care clinic.
Main Outcome Measures. Prevalence and frequency of native healer use. Demographic characteristics of native healer users. Medical reasons for seeking native healer care. Cost of Native healer care. Conflict with conventional medicine.
Results. Sixty-two percent of patients had used native healers in the past, and thirty-nine percent used native healers on a regular basis; users were not distinguishable from non-users by age, education, income, fluency in English, identification of a primary provider, compliance or satisfaction with medical care. Religion did not influence their decision to seek native care unless patients identified themselves as Pentecostal, in which case they tended not to use native healers (p<.001). Patients consulted native healers for common medical conditions such as arthritis, depression and anxiety, and diabetes mellitus, as well as "bad luck." Perceived conflict between native healer advice and medical provider advice was rare. Cost was the main barrier to seeking native healer care.
Conclusions. Native healer use for medical conditions is common and is not limited to any particular age, sex, education level, or income; nor is it correlated with frequency of hospital use, compliance with medical provider instructions, or satisfaction with medical care. Patients are willing to discuss native healer use if asked in a sensitive manner and rarely perceive conflict between native healer and conventional medicine.

ACCULTURATION AND BREAST CANCER SCREENING FOR URBAN HISPANIC WOMEN. Ann S. O'Malley, Jon Kerner, Ayah Johnson, Jeanne Mandelblatt, Georgetown University Medical Center, Washington, DC.

Objectives. We investigate whether acculturation is associated with the receipt of clinical breast exams and mammograms among Colombian, Ecuadorian, Dominican and Puerto Rican women, ages 18-74 in New York City, 1992.

Methods. A bilingual, targeted random-digit dial telephone survey of 908 Hispanic women from a population-based quota sample. Outcome measures include "ever" and "recent" use of clinical breast exams and mammograms. Multivariate logistic regression models assess the effect of acculturation on screening use.

Results. Among respondents qualifying for the survey based on age and ethnicity, the refusal rate was 2.1%. Higher acculturated women had significantly higher odds of ever and recently receiving a clinical breast exam, and of ever having had a mammogram, than less acculturated women (p ≤0.01 for each), controlling for sociodemographic, and health system characteristics, and for cancer attitudes and beliefs. For all screening measures, there was a linear increase in the adjusted probability of screening as one goes from least to most acculturated.

Conclusions. Acculturation is an important factor to consider in attempts to improve breast cancer screening rates among these Hispanic subgroups. These findings suggest that providers consider tailoring their approaches to the acculturation level of the Hispanic women served.

PATIENT AND PROVIDER SATISFACTION WITH METHODS OF INTERPRETATION IN A RESIDENTS' AMBULATORY CARE CLINIC. David Kuo and Mark J. Fagan, Division of General Internal Medicine, Rhode Island Hospital, Brown University School of Medicine, Providence, Rhode Island 02903
Study Purpose: A variety of methods of interpretation (MOI) are used to facilitate communication for Spanish-speaking patients, but no published studies have compared attitudes of patients and providers about existing MOI. We sought to determine satisfaction with MOI among patients and providers in a residents' ambulatory care clinic which serves a significant percentage of Spanish-speaking patients.
Methods: Based on literature review, we created a survey containing questions about perceptions of MOI used in the outpatient setting; specifically, family or friends, professional interpreters, ad hoc interpreters, telephone language services, and the physician. The survey used Likert scale questions to ask about frequency of use of various MOI, satisfaction with MOI, patient comfort using MOI for sensitive topics, and the perceived importance of various characteristics of MOI. The survey was adapted to use with internal medicine residents and Spanish-speaking patients, and administered in Rhode Island Hospital's general internal medicine clinic over a six week period.
Results: 147 patients (96% of those approached) and 49 residents (69.0%) completed the survey. Both groups reported using a variety of MOI, and were most satisfied with professional interpreters (over 90% reporting somewhat or very satisfactory). Patients were significantly more satisfied than residents using family members and friends (85% vs. 56%, p<0.01). For sensitive issues, patients were most comfortable using physicians who were proficient in the patient's language (98% somewhat or very comfortable). Both groups agreed that accuracy, accessibility, and respect for confidentiality were highly important characteristics of interpreters (>88% somewhat or very important). However, patients gave more importance to the ability of the interpreter to assist them after the physician visit (94% vs. 48%, p<0.01).
Conclusions: There are significant differences between physicians and patients with respect to their satisfaction with various methods of interpretation. These results may help resident clinics improve existing systems to meet the needs of Spanish-speaking patients.

IMPACT OF CROSS-CULTURAL PHYSICIAN-PATIENT RELATIONSHIP UPON PATIENT CHOICE OF MEDICAL CARE. RA David and M Desir, Mount Sinai Medical Center, New York N.Y.
OBJECTIVE: Cultural and language differences are known to impact upon health care delivery. We undertook a study to define issues which impact upon a patients utilization of treatment options.
METHODS: An evaluative instrument was developed in English and Spanish as a ten minute survey. Institutional review board approval was obtained. The survey was randomly distributed in a multi-disciplinary primary care ambulatory medicine site located at Mount Sinai Medical Center.
RESULTS: The survey completion rate was 86%. 13 of 15 patients who declined participation stated distrust for the "medical establishment" was their reason, based on racial issues. For categorical data Chi-square analysis was utilized.
38± 11%, (P< .05) of patients indicated their physician took into account their unique cultural needs.
61± 11%, (P< .05) indicated their physician took into account their emotional needs.
44± 11%, (P< .05) of patients indicated that family advice plays a role in their taking their medication.
28± 11%, (P< .05) indicated that their religion or a healer played a role.
73± 11%, (P< .05) of patients use prayer as alternative treatment.
25± 11%, (P< .05) use herbs, plants, or oils without the knowledge of their physician.
52% of women and 26% of men responded that they would be better understood if their physician was of their same gender. 25% of women and 11% of men indicated they would be more likely to follow treatment regimens if their physician was of their same gender.
CONCLUSIONS: Clear communication leading to trust in the physician is an essential ingredient for patients decision-making regarding adherence to medical therapy. It is disturbing to find that some patients verbally indicated their distrust for the "medical establishment" and for that reason declined participation in the study. However, it is important to note that even if differences in culture exist most patients indicated that effort to acknowledge this issue can help bridge the gap.
Herbs, plants, oils, religion and prayer rank amongst treatments in which patients participate but did not notify their physician. Patients frequently do not share information about non-prescription treatments.
More female patients indicated that sharing the same gender with their physician improved their communication. This finding is consistent with other studies in which there was no culture or language barrier. It is known to impact negatively upon completion rates of mammograms and Pap smears.

PREVENTION 99

SCIENTIFIC, POLITICAL AND SOCIAL PRIORITIES FOR THE 21ST CENTURY

ABSTRACT FORM

Name: Ann S. O'Malley

Position: Assistant Professor

Organization: Georgetown University Medical Center

Work Address: 2233 Wisconsin Ave , NW , Suite 440

City: Washington   State: DC   Zip: 20007

Daytime Telephone: (203) 687-0862   FAX: (203) 687-5229

E-Mail: omalleya@gunet.georgetown.edu

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HEALTH INFORMATION SOURCES USED BY A MULTI-ETHNIC POPULATION

Ann S. O'Malley MD, MPH; Jon Kerner PhD; Lenora Johnson MPH, CHES. Georgetown Univ. Med. Ctr.

OBJECTIVES: To identify the health and cancer information sources used by a multiethnic population; to determine whether information sources differ by ethnic subgroup, age, gender and socioeconomic status.
METHOD: A bilingual, targeted random-digit dial telephone survey of 2462 Hispanic (Colombian, Dominican, Ecuadorian and Puerto Rican) and black (Caribbean, Haitian and US-born) persons, aged 18-80 years, from a population-based quota sample in New York City, 1992. Respondents were asked about sources of general health information and of cancer information via validated questions.
RESULTS: The response rate for all calls made was 62.3%. Among respondents qualifying for the survey based on age and ethnicity, the refusal rate for completed interviews was 2.1%. For all ethnic and age groups the highest proportion of respondents (31-63%) volunteered that a doctor or health professional was a source of health information. The next most commonly cited sources of health information for the overall sample were: television (21%), hospitals or doctor's offices (18%), books (17%), magazines (15%), brochures/pamphlets (11%), and radio (8%). Responses on sources of cancer information followed a similar pattern. Black subgroups were all significantly more likely than Hispanic subgroups to get their health information from a doctor or health professional (p=.001). Use of the radio as a source of health information was highest among Haitians (20.8%) Colombians (12.5%) and Dominicans (8.3%) and lowest among US-born blacks (4.2%) (p=.001), but there was no difference in the use of television. TV was an information source among a larger percentage of higher educated (high school graduates: 24.3%) than less educated persons (8 years or less: 14.9%) (p=.001). There was a linear increase in the percentage citing the doctor/health professional, and a decrease in percentage citing TV, as information source with increasing age (p=.001). Less educated persons and more recent immigrants were more likely to report inability to get health information (p=.001). As proportion of life in mainland-U.S. increased, higher percentages cited magazines and lower percentages cited radio (p=.025) as a source of health information (p=.001).
CONCLUSION: Given the variation in sources of health and cancer information, identifying the most commonly used sources is important to health educators' and public health practitioners' efforts to target hard-to-reach populations such as racial and ethnic minorities.

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Primary Care and Receipt of Regular Breast, ~~Cervical and Colorectal~~ Cancer Screening in Low-Income Women.

O'Malley AS, Forrest CF, Mandelblatt J. Georgetown University Medical Center, Lombardi Cancer Center.

Purpose: Despite lower incidence rates for many cancers, low-income minority women have higher rates of cancer mortality, than white and more economically advantaged women do. To examine the specific features of primary care that promote regular use of breast, cervical and colorectal cancer screening for low-income, urban, minority women.

Methods: A bilingual telephone (CATI) survey of a population-based sample of 600 low-income women in Washington, D.C. to be conducted Dec, 1999- Jan, 2000.

Results: Preliminary data have shown that low-income minority women who had a usual source of care, and continuity with a clinician at that site, were significantly more likely to have "ever" and "recently" received pap smears (OR=2.63. p≤.01; OR=2.00 p≤.05), clinical breast exams (OR=2.83. p≤.01; OR=2.65. p≤.01) and mammograms (OR=2.30 p≤.05; 1.40) respectively, than were women without a usual source of care. Data from focus groups show that low-income minority women find particular features of primary care (*accessibility, patient-provider relationship, and comprehensiveness*) especially important. We will conduct a population-based survey to further assess which particular features of primary care were most important to low-income, minority women; and, whether attainment of those features was associated with receipt of regular breast, cervical and colorectal cancer screening.

Conclusions: Survey findings will guide a future intervention that modifies one or more important features of primary care in order to increase breast, cervical, and colorectal cancer screening in community primary care settings.

TYPE name, address, and telephone number of AUTHOR WHO WILL BE PRESENTING the work at ASPO:

NAME Ann S. O'Malley   DEGREE(S) MD, MPH

INSTITUTION Georgetown Univ. Med. Ctr.   DEPARTMENT Oncology, Lombardi Cancer Center

ADDRESS_Suite 440   2233 Wisconsin Ave., N.W.

CITY, STATE, ZIP_Washington, DC   20007

TELEPHONE: 202-687-0862   FAX: 202-687-0305

EMAIL: omalleya@gunet.georgetown.edu

ADDRESS_Suite 440   2233 Wisconsin Ave., N.W.

CITY, STATE, ZIP_Washington, DC   20007

TELEPHONE: 202-687-0862   FAX: 202-687-0305

EMAIL: omalleya@gunet.georgetown.edu

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Title: Does the Structure and Process of Primary Care Affect Low-Income Women's Adherence to Cancer Screening Recommendations?

Authors: Ann S. O'Malley[1] MD, MPH, Christopher B. Forrest[2], MD, PhD, Jeanne Mandelblatt[1], MD, MPH

Purpose: To examine specific features of the structure and process of primary care that promote adherence to breast, cervical and colorectal cancer screening for low-income, predominantly African-American, urban women. **Methods:** A bilingual computer assisted telephone interview of an RDD/LHH combined population-based sample of 1205 low-income, predominantly African-American women age > 40 years in Washington, D.C. conducted Jan-March, 2000. Survey development was informed by focus groups from the same population. Integral features of primary care: continuity (visit-based), length of relationship with a usual source of care, accessibility (organizational, financial and geographic), comprehensiveness of services, and coordination of specialty care as well as aspects of the physician-patient relationship were all assessed with respect to the adherence to cancer screening. **Results:** The survey response rate was 86%. In unadjusted analyses, visit-continuity with the same clinician, and a longer relationship with the usual source of care (longitudinality) were both significantly associated with adherence to all screening tests. In final multivariate models only two primary care variables, continuity of care (visit-continuity), and comprehensiveness of services (counseling) were consistently associated with adherence to screening for all cancers. In adjusted analyses, continuity with a usual source of care* and with a usual doctor that one sees at that place* was strongly associated with adherence to clinical breast exams (OR 4.9* & 8.0* p≤ .01), mammograms (OR 6.4* & 6.4* p≤ .01), and pap smears (OR 2.8* (NS) & 3.9*, p≤ .01) with a trend toward higher colorectal cancer screening (OR 5.8* & 4.4*). Going from uninsured, to public-insured only, to private (may also have public) insurance groups, there was a linear increase in the amount of continuity with a specific clinician at the usual source of care. (mean scores on the continuity index were 2.85 (SD.95), 3.25 (SD 0.85) and 3.42 (SD 0.73) respectively: F =27.24, p=.0001.) While insurance was a significant predictor of receipt of adherent screening for all tests in the unadjusted analyses, once the primary care variables were entered into the models, insurance was no longer significant. (continued next page)

Conclusions: Attainment of "optimal" primary care is strongly associated with adherence to breast, cervical and colorectal cancer screening for urban low income women of color. These findings suggest that insurance is important in assuring adherence to cancer screening services, to the extent that it facilitates the establishment of a continuous relationship with a clinician at a usual source of care which emphasized the features of optimal primary care. Findings will guide a future intervention that emphasizes important features of primary care in order to increase adherence to screening.

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